# Let's talk about psychosis

Steele, Ann

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King's College London

# VOLUME I: MAIN RESEARCH PROJECT AND SERVICE RELATED RESEARCH PROJECT

**Ann Steele**

Department of Psychology, Institute of Psychiatry

King's College London

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# MAIN RESEARCH PROJECT

Let's talk about psychosis

**1st Supervisor:** Professor Paul Chadwick, Institute of Psychiatry

**2nd Supervisor:** Dr Rose McCabe, University of Exeter

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**ABSTRACT**

**Background:** Recent advances in the psychological understanding of psychosis are supplementing the traditional medical model approach to schizophrenia. Furthermore, a patient-centred model of care is being introduced throughout healthcare promoting collaborative care inline with patients' values and preferences. Research suggests that patients with schizophrenia wish to talk about their psychotic symptoms. In contrast psychiatrists may be reluctant to engage in discussion of psychotic symptoms leading to potential difficulties in delivering truly collaborative care.

**Aims:** The current study aims to explore the aspects of psychotic experiences patients wish to discuss in psychiatric consultations, as well as the features on which psychiatrists focus by applying thematic analysis to extracts of naturally occurring, routine outpatient psychiatric consultations between patients with psychosis and their psychiatrists.

**Results:** Sixty-five consultations from a total of 143 contained at least one discussion about a present positive psychotic symptom. Patients with higher clinical levels of positive psychotic symptoms were more likely to discuss psychotic symptoms during the consultation. Both psychiatrists and patients initiated discussions of symptoms, but psychiatrists were more likely to end the discussion. Results of a thematic analysis revealed that the aspects of psychotic symptoms patients described during the psychiatric consultation strongly corresponded with features of psychosis emphasised by cognitive and relational psychological models of psychosis. In contrast psychiatrists focused on topographical characteristics of symptoms, such as frequency and location. Inclusion of discussion of a positive psychotic symptom did not impact on the therapeutic relationship and accounted for approximately 16% of the consultation time.

**Conclusions:** The focus of psychiatrists during discussion of positive psychotic symptoms in consultations does not correspond to the features of psychosis most salient to patients. In order to be more patient-centred the focus and aims of the psychiatric consultation may need to be adjusted to more closely target the concerns of patients.

## 1 INTRODUCTION

### *1.1 Schizophrenia*

Schizophrenia is a severe mental disorder characterised by positive and /or negative psychotic symptoms. Positive psychotic symptoms include unusual beliefs or 'delusions', disorganised speech, and anomalous experiences such as perceptual abnormalities or 'hallucinations'. Negative psychotic symptoms refer to the absence of typical processes or functions and include flattening of affect, avolition, and catatonia. The symptoms cause significant social and occupational dysfunction, with marked deterioration in at least one major area of functioning such as work, interpersonal relations or self-care. In order to receive a diagnosis symptoms must be present for at least one month, with continuous signs of disturbance in occupational or social functioning evident for at least six months. Symptoms cannot be the result of another mental or medical condition, substance misuse or a developmental disorder (DSM-5, APA, 2013). Schizophrenia is diagnosed in approximately 1% of the population and affects equivalent numbers of men and women (Fearon et al., 2006). It has a typical onset in late adolescence, although the age of onset is generally a few years later for women. It is ranked in the top 10 disabling disorders worldwide and the economic costs of schizophrenia to society are high due to loss of earnings and healthcare expenditure (WHO, 2001). Rates of unemployment for people with a diagnosis of schizophrenia have been reported at 79% across six sites in Europe (Thornicroft et al., 2004). Research suggests that, in the long-term, a third of people will recover completely from schizophrenia both symptomatically and socially (Kinderman & Cooke, 2000; WHO, 2001); however, the course is highly variable and for many it is chronic and severely disabling. Approximately 25% of people will only have one episode of schizophrenia, whereas others will experience relapses, with each relapse predicting worse prognosis for recovery. Ten per cent of people with schizophrenia will commit suicide (Heila & Lonnqvist, 2003) and 30% will attempt it (WHO, 2001).

### *1.2 Psychiatric treatment of schizophrenia*

Historically schizophrenia has been viewed as an organic disease, the symptoms of which are fundamentally different from normal human functions. Whereas affective disorders might be seen as an exacerbation or extension of typical cognitive processes or emotions, psychosis was thought to be entirely distinct. Karl Jaspers

(1963) was instrumental in making a distinction between psychosis and neurosis, stating that whereas symptoms of affective illness were “meaningful” the symptoms of psychosis were “ununderstandable, mad in the literal sense”. On this basis Jaspers championed the view that psychotic symptoms should be diagnosed on the basis of their form rather than on their content. This view became accepted in psychiatry, and was systematised by Kurt Schneider in the form of first-rank symptoms (e.g. a hallucination of a running commentary, or bizarre delusional perception), which have long been considered to be particularly characteristic of schizophrenia in diagnostic criteria (e.g. DSM-III; APA, 1980). More recent diagnostic criteria have recognised the lack of specificity of these Schneiderian first-rank symptoms and have eliminated their special status in diagnosis (DSM-5, APA 2013).

Inline with this understanding of psychotic symptoms and the definition of schizophrenia as a biomedical disorder the main treatment approach has been pharmacological. The discovery of neuroleptic drugs, introduced in the 1950s, contributed to a revolution in the care of people with schizophrenia. Their efficacy in reducing or eradicating psychotic symptoms allowed previously disturbed patients to resume relatively normal functioning, living in the community rather than in large institutions, which had been common until this time. Although the neuroleptic drugs were very effective for many people at treating positive psychotic symptoms, they also had the capacity to induce unwanted side effects, in particular disorders of movement such as dystonia and Parkinsonism. Clozapine was introduced in the 1970s as a way to treat psychotic symptoms without producing movement disorders, and a number of other new drugs without this side effect followed in its stead. These new medications are referred to as ‘atypical’ neuroleptics or antipsychotics, and although do not result in movement disorders have other associated side effects such as weight gain, diabetes, reduced sex drive, and cognitive impairment or ‘mental clouding’ (see Kapur & Mamo, 2003, for a comprehensive history of antipsychotic medication). Although the impact of antipsychotic medication has largely been positive for people suffering with schizophrenia this treatment is far from optimal. An over-reliance on antipsychotics in mental healthcare and increasingly high dosage in cases where medication is less effective have given antipsychotic medication an increasingly bad reputation with patients (Lelliott et al., 2002). The negative side effects can be experienced as intolerable and combined with potential long-term damaging effects on physical

health, can result in a justifiable rejection of antipsychotic medication by many patients. In addition, even when medication is effective it does not constitute a long-term 'cure' for psychosis, and symptoms are likely to persist and to be chronic if medication is stopped. On this basis the demand for alternative treatments to medication is increasing.

The traditional, medical model of schizophrenia as an organic disease has guided the construction of explanatory theories and has therefore largely inhibited research into alternative potential factors and treatments. However, the lack of any individual or collective biological markers for schizophrenia (Kapur, Phillips & Insel, 2012), the sub-optimal efficacy and tolerability of anti-psychotic medication and the increasingly recognised patterns of psychological and social vulnerability of patients with psychosis have resulted in the adoption of a more biopsychosocial framework of schizophrenia incorporating the variety of possible causal factors identified to date. Furthermore, a strong critique of the current mental illness diagnostic system, with particular emphasis on the diagnosis of schizophrenia, has been presented in recent years. Bentall (1990; 2006) challenges the diagnosis of schizophrenia as having no reliability or validity as a single disorder, and instead proposes a single symptom approach. Furthermore, Bentall argues against the view of psychotic symptoms as distinct from normal human functions, instead highlighting evidence for symptoms of psychosis occurring in the typical population and therefore being on a dimension with normality (e.g. Romme & Escher, 1989; Peters, Joseph & Garety, 1999) thus championing psychological frameworks for understanding and treating psychotic symptoms. This fundamental shift in thinking about psychotic symptoms has greatly influenced and contributed to the recent surge of research into psychological factors underlying and impacting psychosis.

### *1.3 A psychological understanding of psychosis*

Over the past two decades progress has been made to rectify the gap in psychological understanding and treatments for psychosis. Building on the success of cognitive behaviour therapy (CBT) as a way to understand and treat mood disorders (Beck et al., 1979; Beck, 1975), Chadwick and Birchwood (1994) applied a cognitive model to auditory verbal hallucinations, or 'voices'. In essence the cognitive model of voices proposes that the beliefs a person holds about the voices that they hear influence the levels of distress they experience and therefore impact

the way in which they respond to them. The role of cognitive appraisal in determining the experience of a voice hearer has been evidenced by studies demonstrating that as many as 10% of people who experience auditory verbal hallucinations are not distressed by them and do not require psychiatric help (McCarthy-Jones, 2012). On the basis of this framework CBT for voices emphasises identifying and working with the beliefs a person holds about the voices in order to reduce the distress they experience and any consequential disturbance in their behaviour. This viewpoint is in stark contrast to the biomedical model and has initiated a ground-breaking shift in thinking about psychosis, whereby the individual's own understanding of their psychotic symptoms influences their experience of and reaction to them.

The cognitive model of voices highlights that beliefs about voices experienced as distressing typically include an appraisal of the voices as sentient beings who are interacting with deliberate intent. The intent of the voices, according to the model, is typically interpreted as malevolent rather than benevolent, and to have power over the individual. Evidence has been presented to support the cognitive model (Chadwick & Birchwood, 1995; Mawson, Cohen & Berry, 2010), and recent literature has suggested extending the model to incorporate understandings of voices in terms of appraisals of social rank, whereby perceptions of voice power and superiority have been found to reflect the person's evaluation of their own social status in reality (Birchwood et al., 2004). Although the cognitive model has altered the landscape of understanding of voice hearing some criticism has been levelled at the possible over-focus on perceived power (Close & Garety, 1998), and under-focus on other dimensions of appraisals. For example the importance of the perceived intention (malevolent or benevolent) of the voice and its association with distress has been relatively overlooked thus far (Mawson et al., 2010), and may represent a beneficial focus in therapeutic intervention. In addition, the findings drawing parallels between perceived social rank in relation to voices and social rank more broadly may bare relevance to treatment development. Hayward and colleagues (2013) present an argument for extending the cognitive model towards conceptualising a voice as a social, person-like, stimulus that the voice-hearer has a relationship with, rather than a sensory or thought-like stimulus that the voice-hearer has beliefs about. This conceptualisation points to therapies that prioritise learning to relate to voices in a different way, which is often cited in stories of

recovery of voice hearers (Romme et al., 2009), and provides the framework for Relating Therapy (Hayward et al., 2009).

Delusional thinking has also been the focus of a cognitive therapy approach following evidence for reasoning biases and memory distortions contributing to delusion formation and maintenance. For example, Garety and Hemsley (1994) found that people with delusions had a tendency to 'jump to conclusions' in spite of having access to only limited evidence. Other cognitive biases such as reduced ability to self-monitor thoughts (Frith, 1992) and a tendency towards externalising attributions for events (Kinderman & Bentall, 2000) have also been evidenced. The models of psychosis that have developed on the basis of these findings commonly posit that it is not the unusual experiences themselves that constitute a difficulty for people with psychosis, but instead the appraisal of them as external and distressing (Garety et al., 2001; Morrison & Peterson, 2003). Psychological treatments therefore prioritise understanding the perspective or explanatory model a patient has about their experiences as well as the distress that results from the experience. This stance is fundamentally different from the traditional medical model in psychiatry that categorises psychotic symptoms as distinct from typical functions and ununderstandable or without related meaning for the person, instead recognising and emphasising the importance of the personal meaning of psychotic symptoms to the sufferer and working at this level to help to reduce distress and disturbance.

Overall, psychological treatments for psychotic symptoms, such as CBT (e.g. Chadwick, Birchwood & Trower, 1996; Kingdon & Turkington, 1991) are evolving and have a growing evidence base (e.g. Lewis et al., 2002; Rathod, Phiri & Kingdon, 2010; Sensky et al., 2000; Tarrier et al., 1998; Wykes et al., 2007). They are increasingly recognised and are now recommended in treatment guidelines (NICE, 2014) and offered to patients as an adjunct or alternative to medication. Although psychological theories and therapies for psychotic symptoms are still in their infancy, their relative success in reducing the distress and disturbance caused by psychotic symptoms, as well as their popularity as an alternative for patients for whom pharmacological treatment is ineffective or rejected, implies that psychological aspects of psychotic symptoms are important to patients, and a greater understanding of these aspects might further benefit psychiatric treatment also.

### *1.4 Patient-centred care*

In recent years there has been a shift towards a more 'patient-centred' approach to treatment in physical healthcare whereby patients' own views are considered in treatment and greater emphasis is placed on adhering to patients' wishes (Mead & Bower, 2000). This model of care places greater emphasis on the patient's involvement in determining the goals of treatment that are meaningful to them and the nature of their care. Meaningful goals for patients generally go beyond symptoms to include quality of life, functioning, and a sense of hope and self-efficacy. Patient-centred care shifts the balance of authority and responsibility of the doctor-patient relationship and incorporates shared decision making (SDM) between the clinician and the patient, particularly when it comes to treatment. SDM involves patients being given information about a number of options regarding their care, and subsequently being supported in making their own decision about which option to pursue based on their own values and preferences. Practicing SDM requires that clinicians assess the patient's interest in participating in decisions, provide information to them on the risks and benefits of specific treatments or approaches in an understandable format, and have discussions with them regarding these choices. Directly involving patients in decisions regarding their healthcare is increasingly recognised as good practice in medicine and is now being broadly recommended in guidelines and in new training schemes for clinicians (Department of Health, 2010; 2012).

Furthermore, the principles of patient-centred care, where patients' involvement in their own care is encouraged, are also being adopted in mental health care and in psychiatry (e.g. NICE, 2014). However, many would argue that the current practice in psychiatry is not patient-centred enough. The 'recovery movement' strongly advocates a more explicit shift towards the needs and views of patients in the treatment of chronic and debilitating mental health problems. Within this paradigm 'recovery' is defined as a personal process of tackling the adverse impacts of experiencing mental health problems, despite their continuing or long-term presence. It involves personal development and change, including acceptance, a sense of involvement and control over one's own life, the cultivation of hope and using the support of others, including direct collaboration in joint problem-solving between the individual and those involved in their recovery (Deegan, 1996; 2003; Jacobsen & Greenley, 2001). The recovery movement promotes the patient's own perception of their quality of life as a gauge of the efficacy of their treatment, as an

alternative to a more medical 'symptom-free' definition of recovery, and therefore challenges traditional psychiatric service approaches to the treatment of schizophrenia. The implications of employing a recovery approach in mental health services are broad, but at even the most basic level would require service providers to rescind their power and authority and to view and measure outcomes differently. Psychiatric care has become increasingly holistic in recent years, encompassing consideration of a patient's daily living and social needs, employment, general health, risk to self and others and other factors such as substance misuse, in addition to the more traditional focus on symptoms and medication. However, in psychiatry, as is the case in physical healthcare, there is still a tension between even a less radical patient-centred model of care and the more traditional paternalistic approach to delivering treatment that healthcare services have been modelled upon.

In the case of schizophrenia in particular, even when compared with other mental health problems, the reliance on a biological framework of explanation and treatment is more entrenched in psychiatric practice. The traditional medical view of schizophrenia as a disorder that reduces or totally eradicates a person's connection to reality and therefore their ability to demonstrate rational judgment and decision-making is still deep-rooted. Therefore, it is understandable that psychiatrists express concern when asked to adjust their practice to incorporate the views of their patients, especially when the patient's viewpoint might strongly depart from the medical stance, and may appear to represent a lack of 'insight' as well as risky decision-making. Davidson and colleagues (2006) evaluated some of the resistance presented by clinicians in response to the introduction of a recovery-oriented system of mental healthcare implemented in Connecticut in the USA. Although many objections were commonly raised, the most prominent concerned the appropriateness of affording choice to patients with mania or psychosis whose judgment and reasoning is thought to be impaired, and the risk to the service provider of holding responsibility for the potentially impaired decision-making of these patients.

### *1.5 Talking about psychosis*

Although this wider debate will continue, it is important to acknowledge that patient-centred care can be delivered at levels other than just the service level

including the point of delivery, for example the psychiatric consultation. According to a patient-centred model the concerns and interests of the patient, as well as those of the psychiatrist, should form the basis of a consultation (Mead & Bower, 2000). The findings in the fields of psychology and recovery literature that patients often experience significant distress in response to psychotic symptoms, and that this in turn causes disturbance in their behaviour and other aspects of their life, implies that one area of considerable concern to patients is likely to be their experience of psychotic symptoms. However, talking with patients about psychotic symptoms may present a particular challenge for psychiatrists, possibly in large part due to the historical view that there is no clinical relevance or need to explore the content of a patient's psychotic symptoms (e.g. Mayer-Gross, Slater & Roth, 1954).

Research into this phenomenon has evidenced a difficulty for psychiatrists in talking about psychotic symptoms. McCabe and colleagues (2002) used conversation analysis techniques to examine the recordings and written transcripts of 32 outpatient consultations between patients with schizophrenia or schizoaffective disorder and their psychiatrists. In the study discussion of psychotic symptoms occurred on average between one to two times during each consultation, and lasted on average for 67 seconds. Patients and psychiatrists raised the topic of psychotic symptoms equally frequently; however, whereas psychiatrists asked questions regarding the frequency or severity of the symptoms in relation to medication, patients endeavoured to talk about the content and emotional consequences of their symptoms. In response to patients' attempts to discuss these aspects of psychotic symptoms psychiatrists had a tendency to hesitate and avoid answering questions about symptoms, demonstrating a reluctance to engage in the discussion of psychotic symptoms at this level. Furthermore, when a carer was present, psychiatrists often smiled or laughed in response to patients' comments or questions about psychotic symptoms, seemingly demonstrating embarrassment and difficulty in the interaction. The authors suggest that one possible reason for the reluctance of psychiatrists to talk about psychotic symptoms is an institutional belief that it is not helpful or productive to deal with the content of patients' psychotic symptoms. However, rather than benefitting the interaction by avoiding sensitive issues that might result in disagreement or distress, psychiatrist avoidance of symptom discussion appeared to result in explicit confrontation and disagreement. In the short- and long-term such difficulties in interaction have the potential to

negatively impact the therapeutic relationship and patient engagement with treatment and services more generally.

To date no systematic research has explicitly posed the question directly to psychiatrists as to why they might wish to avoid discussing certain aspects of psychotic symptoms with their patients. Hinshelwood (1999) explores the difficulty that clinicians have with regards to engaging with psychotic and other "difficult" patients. In his paper Hinshelwood highlights that the scientific approach psychiatrists adopt in the understanding and treatment of patients with psychosis, alongside the difficulty in sharing meaning with these patients whose experiences are alien to one's own, encourages a reductionist stance that results in the depersonalisation of the patient by the clinician. This instinct to emotionally distance oneself from a patient with psychosis might explain a reluctance to explore the personal meaning and emotional experiences associated with psychotic symptoms. Other possible reasons that might prevent a psychiatrist from engaging in discussion of psychotic symptoms might include a fear of inadvertently colluding with and therefore encouraging the patient in their beliefs, or a wish to avoid revisiting old ground on which agreements have not been reached in the past. In practical terms, psychiatrists may also be concerned with the amount of time a discussion of psychotic symptoms might take; a reasonable concern in the context of over-stretched services with already limited consultation times. In addition, psychiatrists have the added burden of bearing clinical responsibility for a patient's safety as well as the safety of others in relation to the patient and this is likely to inhibit their willingness to deviate from their typical practice.

One obstacle for psychiatrists is that, despite the frequency with which they work with patients experiencing psychosis, there are no evidence-based guidelines on how they should respond to discussion of psychotic symptoms. Whereas the traditional medical model, which has strongly influenced diagnostic guidelines used by psychiatrists in daily practice, advocates exploring only the form and not the content of psychotic symptoms, newer psychological approaches are founded on understanding the personal meaning and emotional consequences of psychotic symptoms. Psychiatrists are not necessarily trained in psychological approaches, and the aims and objectives of their work with patients are different from those of psychotherapists. In addition the context within which they work differs from that of

psychotherapists insofar as they might have more infrequent contact with patients, significantly shorter sessions, and consultations that may include other professionals or carers. As such it could not be expected of psychiatrists to employ the same practices as psychotherapists. However, given the movement towards patient-centred care, in combination with advances in psychological understanding and treatment approaches for psychosis, it is possible that there is room for further optimisation of the current psychiatric approach that is more inline with patient-centred and psychological models of care.

### *1.6 Why talk about psychosis?*

In spite of the perceived difficulty there are many reasons why engaging with discussion around psychotic symptoms might be a good idea for psychiatrists. Firstly, there is evidence suggesting that patients wish to talk about their psychotic symptoms. For example the success and popularity of psychological therapies for psychosis indicate a wish by patients to discuss the content and emotional consequences of their psychotic symptoms. Furthermore the growing number of charities and groups initiated by patients and carers that provide opportunities to talk about psychotic symptoms highlights the demand for this aspect of the illness to be addressed. A good example of this is the Hearing Voices Movement, an international movement that aims to create opportunities for voice hearers to share their experiences and understanding of hearing voices. Hearing voices groups provide a safe space within which to openly discuss the experience of hearing voices without being criticised or rejected. Exploration of the meaning and background of the voices is encouraged, as is the sharing of coping strategies (Escher & Romme, 2012). According to this movement, mental health professionals need also to accept that auditory hallucinations in the form of voices may have a personal meaning to the hearer, in that voices can often be linked to the voice hearer's prior life experiences. On this basis it is recommended that the content of voices should not be simply ignored or removed (with the use of medication), but instead explored to elucidate the meaning and to inform self-help coping strategies. It might be argued that patients wish to talk about psychotic symptoms only in the context of psychotherapy or support groups; however, in the study by McCabe and colleagues (2002), patients were found to repeatedly attempt to raise the content and emotional consequences of their hallucinations and delusions in psychiatric consultations. This would suggest that these issues are salient to patients in the

psychiatric setting as well. Moreover, in spite of recommendations (e.g. NICE, 2014) psychotherapy for psychosis is not yet widely available or referred for (Hansen, Kingdon & Turkington, 2006; Kingdon & Kirschen, 2006), suggesting that access to psychotherapy cannot be relied upon for those patients who wish to discuss their psychotic experiences in this way.

Another reason why talking about psychotic symptoms might be beneficial in psychiatry is that it could directly or indirectly result in better clinical outcomes by impacting the therapeutic relationship. The relationship between the patient and the therapist has mainly been studied in the practice of psychotherapy and has been consistently found to predict the outcome of therapy (Martin, Garske & Davic, 2000); however, it is also central to psychiatric practice as a means of engagement with services and treatment. Research has provided evidence for an effect of the therapeutic relationship on outcomes of psychiatric treatment in patients with psychosis (Priebe et al., 2011). One of the biggest difficulties in the treatment of patients with psychosis from the perspective of psychiatrists is poor adherence to medication. Studies have shown rates of non-adherence to antipsychotic medication at approximately 50% (Lacro et al., 2002), and periods of complete discontinuation of medication have been evidenced in as many as 74% of patients in both outpatient and inpatient settings (Lieberman et al., 2005). In a large-scale European multi-centre study, McCabe and colleagues (2012) found that a better therapeutic relationship between patients and their psychiatrists was associated with better adherence to medication, irrespective of whether the relationship was rated by the patient or the clinician. Therefore, if talking about the issues that are of primary concern to the patient, as well as those of the psychiatrist, benefits the therapeutic relationship, it is reasonable to suppose that this might positively impact on other clinical outcomes as well.

### *1.7 The current study*

Psychosis has long been an enigma in the field of mental health, and one area that many still regard with fascination. Although research into the psychological and experiential aspects of psychosis is growing there is still much that is not understood about the way in which patients experience psychosis. Indeed, psychotic symptoms, perhaps more than any other symptoms of mental or physical ill health, are highly idiosyncratic and varied. In the field of psychiatry a traditional medical model still

heavily influences the treatment of psychosis. Although there are established benefits to this approach, including the relative success of antipsychotic treatment over the last half century, pharmacological treatment of psychosis is still far from optimal. Furthermore, changing attitudes about the provision and delivery of both physical and mental healthcare, advocate increased inclusion of patient values and choice above those of the clinician - presenting a difficult shift for psychiatrists in their treatment of patients with diagnoses of schizophrenia. Further knowledge about the concerns or appraisals of patients regarding their psychotic symptoms and the issues that patients regard as salient enough to raise in psychiatric consultation would add to the expanding body of literature considering the phenomenological experience of psychotic symptoms as well as possible implications of this for psychiatric treatment delivery from a more patient-centred perspective. Evidence points to a wish by patients to talk about the meaning and emotional consequences of their psychotic symptoms both in and out of the psychiatric context; yet this is at odds with a traditional psychiatric treatment model for psychosis, and can result in difficulties between psychiatrists and their patients during consultations. Little is yet known about how psychiatrists elicit and respond to patient's views or concerns about psychotic symptoms. Some evidence suggests that psychiatrists are reluctant to engage with patients about psychosis perhaps due to perceived constraints of time, as well as fear of collusion, disagreement and increasing risk. No research has yet explored whether or not these risks are real or perceived, and to date there are no evidence-based recommendations or guidelines for psychiatrists to shape their practice in this area. In accordance with a patient-centred model of care, an approach that acknowledges the patient's appraisals of and associated emotional response to psychotic symptoms might be beneficial both to the patient and to the psychiatrist by improving communication and the therapeutic relationship which in turn might impact on other outcomes such as patient satisfaction and adherence to treatment. Much research has established the importance of the patient's perspective when working with psychosis, and this understanding could now be extended to psychiatry.

One way to explore some of these questions is through observation and qualitative analysis of real-life consultations between patients with psychosis and their psychiatrists. This method provides rich data that gives the opportunity to explore the descriptions that patients give to psychiatrists of their psychotic symptoms in a

naturalistic setting. This could give clues about patients' interpretations of the meaning of their psychotic symptoms as well as possible concerns they may have. In addition, it provides information about how psychiatrists respond to these discussions, and the impact of the discussion of psychotic symptoms on the consultation itself and on outcomes of the consultation such as the therapeutic relationship. Previous studies have successfully used this medium of research in order to explore communication about psychosis from the psychiatrist perspective (McCabe et al., 2002), and a growing body of literature is now relying on qualitative research methods to study aspects of healthcare more broadly (e.g. Drew, Chatwin & Collins, 2001).

### *1.8 Main questions*

The current study aims to explore how patients with psychosis talk about their positive psychotic symptoms with psychiatrists using observation and thematic analysis of naturally occurring routine outpatient consultations between patients with psychosis and their psychiatrists. The focus will be on positive symptoms of psychosis as they are typically considered to be the defining, first-rank features of psychosis. In addition, discussions of positive psychotic symptoms are more easily distinguishable than that of negative psychotic symptoms, resulting in a more methodologically robust approach.

Thematic analysis, by its nature, is exploratory and requires very open questions initially, allowing the main themes of the data to emerge during the process of analysis itself. Therefore, in the first instance, the analysis was broadly based around two main questions:

1) How do patients describe their experience of positive psychotic symptoms within routine psychiatric consultation?

2) How do psychiatrists respond to patients' descriptions of their experiences of positive psychotic symptoms?

## 2 METHODS

### *2.1 Data and participants*

Data were collected as part of two larger studies exploring communication between psychiatrists and patients with a psychotic illness in routine outpatient psychiatric consultations. The main study of the two from which data were drawn was a Randomised Controlled Trial (RCT) investigating the efficacy of a communication skills training programme for psychiatrists. Data used in the current study were only drawn from the baseline consultations, which were recorded before the training was provided, so as not to be affected by the training received by psychiatrists. The author, AS, was a Research Assistant on this study and in this role supported with trial organisation and recruitment. The current study represents an independent analysis of a subset of the data collected as part of the two larger studies.

All consultations took place in East London in the normal consultation rooms of the psychiatrists and were video- and audio- recorded using a digital video camera and a dictaphone set up and switched on prior to the start of the consultation. All aspects of the consultation (including time, length, venue, content and style) were intended to remain unchanged by inclusion in the study and to be uninfluenced by the recording as far as possible.

Participants were consultant psychiatrists and higher-level psychiatry trainees (ST4-6). Following their recruitment the psychiatrists identified patients on their caseloads meeting ICD-10 criteria for a diagnosis of schizophrenia or schizoaffective disorder and who were being seen regularly in outpatient services within the community. Patients were excluded on the basis of substance misuse, organic brain disorder or needing an interpreter. Consent was received from psychiatrists and patients prior to their participation. Ethical approval for the projects was granted at the time of original application and the current analysis was approved under the criteria of the original ethical approval (see Appendix D for approval letter).

In total 143 consultations were included in the corpus of data. Consultations ranged in length between 5 – 42 minutes with an average length of 19 minutes. In some of the consultations other people were present apart from the psychiatrist and patient including the patient's carer, family or other members of their care team such as key workers. Consultations were not excluded from the analysis on this basis. A typical consultation covered a range of topics including review of the patient's mental state,

medication and associated side-effects, living arrangements and home management, social activities, and daytime activities (e.g. day centre attendance or work).

### *2.2 Measures*

*The Positive and Negative Syndrome Scale for Schizophrenia* (PANSS; Kay, Fiszbein & Opler, 1987).

The PANSS is an approximately 45-minute clinical interview on which the patient is rated on a 7-point Likert-scale on 30 different symptoms that make up three subscales, the positive scale, negative scale, and general psychopathology scale. The positive and negative scales each contain seven items including delusions, conceptual disorganisation, hallucinations, hyperactivity, grandiosity, suspiciousness/ persecution, and hostility (positive scale, score range 7 – 49), and blunted affect, emotional withdrawal, poor rapport, passive/ apathetic social withdrawal, difficulty in abstract thinking, lack of spontaneity and flow of conversation, and stereotyped thinking (negative scale, score range 7 – 49). The general psychopathology scale (score range 16 – 112) is made up of 16 items and includes somatic concern, anxiety, guilt feelings, tension, mannerisms and posturing, depression, motor retardation, uncooperativeness, unusual thought content, disorientation, poor attention, lack of judgment and insight, disturbance of volition, poor impulse control, preoccupation and active social avoidance. Scores are often given for each subscale separately, with a total score ranging from 30 – 210. Higher scores indicate increased psychopathology. In their original publication of the PANSS scale, Kay and colleagues (1987) assessed 101 patients with a diagnosis of schizophrenia and reported mean scores of positive scale = 18.20, negative scale = 21.01, and general psychopathology = 37.74. Widespread use and testing has found the PANSS to be a valid and psychometrically sound assessment of schizophrenia symptoms. The PANSS was conducted directly with patients by trained researchers who were not involved in the patient's treatment and who were unaware of the content of the psychiatric consultation.

*Scale To Assess Therapeutic Relationships in Community Mental Health Care* (STAR; McGuire-Snieckus et al., 2007).

The STAR is a measure of the clinician – patient therapeutic relationship in community psychiatry. There are two versions; clinician and patient. Each scale is

made up of 12 items comprising three subscales: 'positive collaboration' and 'positive clinician input' in both versions, 'non-supportive clinician input' in the patient version, and 'emotional difficulties' in the clinician version. Each scale requires approximately 5 minutes to complete, with the participant indicating the degree to which each statement describes their experience with the patient/ clinician (0 = Never; 1 = Rarely; 2 = Sometimes; 3 = Often; 4 = Always). Higher scores indicate better therapeutic relationship, with the exception of the subscales emotional difficulties and non-supportive clinician input, whereby higher scores mean higher degrees of these negative factors. However, scores on these scales are reversed before inclusion in the total score, resulting in higher total scores demonstrating a better therapeutic relationship. The total score ranges from 0 – 48. The authors report good reliability for both scales (r = 0.68 – 0.76). Each psychiatrist and patient completed the STAR immediately following the consultation. (See Appendix A for all measures).

### *2.3 Design and methods*

Due to the magnitude of the data an approach combining descriptive quantitative and qualitative methodologies was thought to be most appropriate. A descriptive quantitative approach was used to present clinical and demographic details of participants, to do basic, statistical comparisons between groups, and to give quantitative summaries of the qualitative data. A qualitative approach was chosen in order to explore in more detail the breadth of themes arising in naturally occurring conversation between psychiatrists and patients with a psychotic illness when discussing positive psychotic symptoms. Given the research questions it was felt that an exploratory, qualitative approach of this nature was likely to reveal, via their descriptions, patients' genuine experiences of and beliefs, feelings and concerns about their psychotic symptoms, as well as providing further information about the responses of psychiatrists and the nature of psychiatric consultations in general. The strong focus on participant experiences and priorities that is characteristic of qualitative approaches was felt to be particularly appropriate for conducting research exploring psychotic experiences from the patient perspective without skewing the data via the use of pre-designed interviews or questionnaire measures which might reflect the views of mental health professionals and researchers whilst limiting or excluding those of patients themselves. Using naturally occurring consultations also had the benefit of increasing ecological validity. The decision not

to include initial consultations, but to focus instead on routine consultations, was also inline with this rationale in that initial consultations can be quite structured and prescriptive and may include measures such as a diagnostic interview. It was felt that routine consultations were likely to have a relatively open structure, and would therefore provide a more natural context within which to explore both the patients' and psychiatrists' perspectives in the consultation.

A thematic analysis approach was chosen as a methodological framework for the qualitative data analysis. Thematic analysis has often been considered to be only an initial stage of a more complex qualitative analysis; however, Braun and Clarke (2006) make the argument for thematic analysis as a useful and flexible research tool capable of providing a detailed, rich and complex account of data and suitable as a methodology in its own right. Braun and Clarke also highlight the importance of the researcher declaring their theoretical orientation in advance of conducting and presenting a thematic analysis. The current study represents a 'theoretical' or deductive approach to the thematic analysis, which is driven by a theoretical interest in one particular aspect of the data, in this case the discussion of positive psychotic symptoms, and holding in mind broad research questions to focus the analysis. In contrast would be a more inductive approach, an entirely data driven method that is not influenced by a researcher's particular interest, questions or preconceptions. In the current study themes were identified at the semantic level, whereby meaning was interpreted at the surface level of the data based on that which was explicit in the language used by participants. Analysis at the latent level would aim to go beyond the semantic level to examine underlying ideas and assumptions theorised as shaping the semantic content; however, this level of analysis was not appropriate or necessary in light of the research questions posed. Therefore the overarching theoretical position of the current study was essentialist or realist, whereby motivations, experience and meaning are able to be theorised easily from the data on the basis of the assumption that a simple, linear relationship exists between meaning, experience and language and thus language reflects meaning and experience. It is the aim of the study to consider the reality of positive psychotic symptoms to the participants through an exploration of their descriptions of their experiences and the meanings they attach to them.

Elliott, Fischer and Rennie (1999) present a set of guidelines for conducting and

reviewing qualitative research in order to promote and maintain quality control in this field. These guidelines were adhered to in the current project and are inclusive of (but not exclusive to); 'owning one's perspective', whereby authors specify their theoretical orientation and personal anticipations of the data; 'situating the sample', in which authors should describe characteristics of the participants and their circumstances that are relevant to the study; 'grounding in examples', where authors should aim to provide examples of the data both to illustrate the analytic procedures used in the study and to demonstrate how understanding has been reached in light of them; and 'providing credibility checks', where credibility of themes, categories or accounts should be checked. In addition Elliott and colleagues recommend that studies should aim to achieve 'coherence', whereby an understanding should be presented in a way that is coherent and integrated, whilst maintaining the detail in the data; 'accomplishing general versus specific research tasks', in which the researcher should either use an appropriate range of instances (e.g. participants) on which to base a *general* understanding of the phenomenon in question, or study and describe a *specific* instance or case systematically and comprehensively enough to provide a reader a basis for an understanding of that case; and finally 'resonating with readers', in that the report should be judged by readers to accurately represent the subject matter and be presented in a way that promotes interest and a clarification or enhancement of the reader's understanding and appreciation of the topic.

### *2.4. Procedure and analysis*

#### *2.4.1 Owning one's perspective*

The thematic analysis was conducted by the author, AS, who is a clinical psychologist in the final year of her training. Prior to the clinical doctorate training AS had a background in psychological research. Of relevance to the current study, AS spent one year assisting in setting up one of the two research projects from which the current data corpus is drawn. In this capacity AS developed an interest in how psychiatrists communicate with patients with psychosis and ways in which this might be improved upon in current practice in the NHS. In this regard it is important to state a potential bias towards a critical appraisal of psychiatrists in this context. However, the main question of the current study focuses primarily on the views and experiences expressed by patients when describing their psychotic symptoms, an area of relative novelty to AS, and as such has been approached with objectivity as

far as is possible in any qualitative analysis. It is worth considering however, that the training and ethos of clinical psychology prioritises the individual formulation of each patient's needs based in large part on their own subjective experiences of them, arguably to a greater degree than psychiatrists who are trained within a more traditional medical model of psychiatric illness. The analysis conducted in the current study is likely to reflect these inherent views.

*2.4.2 Resources*

Analysis was conducted on written transcripts of the consultations using a computer software programme called 'Dedoose' suitable for the analysis of mixed-methods research incorporating both quantitative and qualitative data. The software enabled both the extraction of individual data extracts from larger data items, and the coding of extracts using an evolving and extensive list of self-defined codes. Codes could be further delineated into subcodes, allowing for broader themes, incorporating a number of subcodes, to evolve during the analysis.

*2.4.3 Phases of analysis*

In order to promote the use and benefits of thematic analysis, and avoid criticism of the technique as loose and lacking in methodological rigor (e.g. Antaki et al., 2001), Braun and Clarke present a step-by-step guide of the phases through which researchers should aim to pass in order to produce a good thematic analysis. These phases include familiarising yourself with the data (including transcription of verbal data); generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report. This procedure allows a clear demarcation of thematic analysis, providing researchers with a well-defined explanation of how it is carried out whilst maintaining the 'flexibility' tied to its epistemological position. Braun and Clarke emphasise the need for clarity around process and practice of thematic analysis. On the basis of these recommendations the phases of the current thematic analysis are described in detail here. Although the procedure is described in phases, overlap occurred across the phases as is customary in qualitative analysis. The iterative manner of this analysis, moving forwards and backwards through different stages as theoretical ideas were developed and new data came to light, is a cornerstone of good thematic analysis.

*Phase 1:* Extraction and familiarising self with the data

The first phase of the analysis involved creating a data set from the original data

corpus. In order to do this, all segments of the consultations that included the first instance of a discussion on the topic of one of the patient's psychotic symptoms were extracted. Where there was discussion of more than one psychotic symptom during the consultation, the initial discussion of each separate symptom was extracted. The beginning of an extract was marked as the first utterance by either patient or psychiatrist referring to a present positive psychotic symptom. In cases where the topic of positive psychotic symptoms was raised but were reported not to be present (e.g. when a psychiatrist asked about the presence of voices and the patient denied them) the discussion was not extracted. The end of an extract was marked when the main topic of conversation changed away from the psychotic symptom. In some cases a change of topic was ambiguous, for example when a conversation about voices moved on to anti-psychotic medication. In these cases when the main focus of the conversation remained on the psychotic symptom itself (e.g. the effect of medication on the voices) it was included as part of the discussion about psychotic symptoms. However, if the main topic changed away from the psychotic symptom (e.g. to dosage or side effects of medication) this was counted as a change of topic and the extract was ended at this point. As a rule of thumb once the topic change had occurred and the topic was not revisited within the next five utterances by either the psychiatrist or the patient this was recorded as the end of the extract.

To provide an initial credibility check, 10% of the consultations were independently rated for content that included initial discussion of a psychotic symptom by a second rater in order to establish inter-rater reliability. That is, agreement was established on identification of a first discussion of a positive psychotic symptom.

This initial phase of extraction served the purposes of both familiarising AS with the data, and generating initial codes. In addition the reflective process began at the same time as the extraction and notes were made throughout in order to record initial reflections and impressions. Each full consultation transcript was read at least twice in order to comprehensively identify all relevant discussions of positive psychotic symptoms meeting criteria for extraction.

*Phase 2:* Generating initial codes

Once the data set of discussions of positive psychotic symptoms was fully extracted, the analysis moved into the second phase, which involved coding. Building on the

reflections, impressions and initial codes generated in the extraction phase, the extracts were read numerous times, moving towards data immersion, and codes were applied identifying features of the data felt to be pertinent to the main research questions. Extracts were given equal attention in order for repeated patterns within the data to be given full consideration and for coding to be comprehensive across all extracts (see Appendix B for an example of a coded extract).

*Phase 3:* Searching for and reviewing themes

As the analysis process continued into the third stage, broader themes began to emerge, explaining larger sections of the data by combining closely related codes. Previously coded extracts were revisited with a view to checking these new themes. Salient codes relevant to the research question were incorporated into a theme, for example the theme emotional response of the patient to psychotic symptoms combined commonly cited emotions including distress and fear. However, codes that were too diverse or did not have enough data to support them were discarded as in the case of the code 'duration of hallucination' which was only discussed in one consultation and did not therefore represent a significant code or theme. This refinement of themes occurred primarily with the coded data, to ensure they formed a coherent pattern, and secondly the themes were considered in relation to the overall data set. This method ensured that the themes accurately reflected the patterns in the data set as a whole. The extracts were checked once more following the finalisation of codes and themes to guarantee comprehensive coding throughout. Consideration was given to how the themes were organised in relation to each other and thematic maps were generated in order to aid the visualisation of links and relationships between themes.

*Phase 4:* Defining and naming themes

Once the themes and their organisation in relation to one another were clear, the penultimate phase of the analysis involved defining and naming the themes in a way that would immediately convey their essence. Each theme was clearly defined and accompanied by a detailed description.

*Phase 5:* Producing the report

The final phase of the analysis was producing the report including a comprehensive description of the procedure of data analysis as well as clear definition and

explanation of each theme. Consideration was given both to describing individual themes as well as their relation to each other and to the story evident in the data as a whole. Examples of extracted transcripts were chosen to demonstrate aspects of the themes and to present clear examples of the idea being presented.

## 3 RESULTS

### *3.1 Quantitative descriptive analysis*

*3.1.1 Extracts of consultations*

Of the 143 consultations included in the full data corpus, 65 contained at least one discussion of a present, positive, psychotic symptom, yielding 86 extracts in total. Forty-six consultations contained one extract, 18 included two, and one consultation included four extracts. In consultations where more than one segment was extracted each extract included discussion of a different positive psychotic symptom. In 78 consultations there was no discussion of a present positive symptom, which in the majority of cases reflected a denial by the patient of the presence of any current psychotic symptoms, rather than no mention of psychotic symptoms within the consultation. Discussions of psychotic symptoms ranged from 20 seconds to 14 minutes 12 seconds, with the average length being 3 minutes 9 seconds. Proportionately discussion of psychotic symptoms equated to an average of 16% of the consultation time. To establish reliability a second rater extracted discussions of psychotic symptoms from 10% (15) or the consultations. Initial agreement was reached on 85% of the extracts, a high level of inter-rater reliability. Furthermore, following discussion of the criteria for extraction agreement was reached on the remaining 15% of extracts.

Who initiated discussion of the psychotic symptom and who it was ended by was coded on the basis of who made the first explicit or implicit reference to the psychotic symptom and who changed the topic away form the psychotic symptom. A second rater rated 10% (9) of the extracts achieving 94% agreement. Psychiatrists both initiated and ended more discussions of psychotic symptoms than patients, although this contrast was more striking for who ended the discussion with 77% of discussions being ended by psychiatrists compared to 17% being ended by patients (see Table 1 for figures).

**Table 1.** Initiation and ending of symptom discussion.

| | **Patient (%)** | **Psychiatrist (%)** | **Other (%)** | **Patient & Psychiatrist (%)** |
|---|---|---|---|---|
| **Initiated by** | 32 (37%) | 52 (60%) | 2 (2%) | 0 (0%) |
| **Ended by** | 15 (17%) | 66 (77%) | 2 (2%) | 3 (3%) |

Furthermore, the number of discussions both initiated by and ended by the patient or psychiatrist and the number initiated by one and ended by the other were calculated and are displayed in Table 2. The largest proportion of discussions (45%) were both initiated and ended by the psychiatrist; however a large number were also initiated by the patient but ended by the psychiatrist (31%). The patient both initiated and ended the discussion in very few cases (5%), whereas the psychiatrist initiated and the patient ended the discussion in more instances (12%). In some cases a carer initiated and/ or ended the discussion.

**Table 2.** Proportion of symptom discussions initiated and ended by the psychiatrist, the patient, or both.

| | | **Initiated by** | |
|---|---|---|---|
| | | **Patient** | **Psychiatrist** |
| **Ended by** | **Patient** | 4 | 10 |
| | **Psychiatrist** | 27 | 39 |

*3.1.2 Patient and psychiatrist demographics and clinical characteristics*

The 65 consultations including discussion of a positive psychotic symptom were conducted by a total of 29 psychiatrists, of whom 23 were male. The length of the relationship between the psychiatrist and the patient varied and ranged from many years to first time of meeting. A carer or other person was present in 18 of the consultations. The majority of patients were male, single and unemployed. Demographic details of the 65 patients can be found in Table 3.

**Table 3.** Patient demographics.

| | N |
|---|---|
| **Gender** | |
| Female | 16 |
| Male | 49 |
| **Ethnicity** | |
| White British or Irish | 25 |
| Other White Background | 3 |
| Asian or Asian British | 11 |
| Black or Black British | 17 |
| Chinese | 1 |
| Mixed Background | 4 |
| Other Ethnic Group | 3 |
| Not Disclosed | 1 |
| **Marital Status** | |
| Single | 48 |
| Married/ Partnership | 11 |
| Separated/ Divorced | 4 |
| Widowed | 1 |
| Not Known | 1 |
| **First Language** | |
| English | 50 |
| Other | 14 |
| Not known | 1 |
| **Employment Status** | |
| Unemployed | 47 |
| Voluntary Employment | 5 |
| Paid or Self-Employment | 3 |
| Supported Employment | 1 |
| Student | 3 |
| Retired | 4 |
| Other | 1 |
| **Mean Age in Years (*Range/ SD*)** | 44 (*23-67/ 10.2*) |
| **Psychiatric Hospital Admissions** | |
| Mean No. of Previous Admissions (*Range/ SD*) | 3.8 (*0-50 / 7.1*) |
| Mean No. of Compulsory Admissions (*Range / SD*) | 1.31 (*0-8/ 1.67*) |
| Mean No. of Weeks Spent in Hospital (*Range/ SD*) | 29.46 (*0-250, 51.12*) |

*3.1.3 Group comparisons*

The group of patients whose consultation included symptom discussion were compared to the group whose consultation did not include symptom discussion in order to establish whether there were fundamental differences between these two groups. Chi squared tests for independence and t-tests indicated no differences between the groups on any demographic variables including age, gender, ethnicity, marital status, first language or employment status. In terms of clinical characteristics there were no differences between groups in illness history including weeks spent in hospital, number of hospital admissions or number of compulsory hospital admissions. However, clinical differences were evident between the two groups according to their scores on the PANSS whereby those patients whose consultation included discussion of present psychotic symptoms had significantly higher scores on the PANSS positive symptom scale ($t$ (143) = -6.13, $p$ = .000) and the PANSS general psychopathology scale ($t$ (143) = -3.87, $p$ = .000) than those whose consultation had no discussion of present psychotic symptoms. Overall there was a significant difference between the groups in the total score of the PANSS ($t$ (136) = -15.19, $p$ = .000), but there was no significant difference between the groups on the PANSS negative symptom scale (see Table 4 for summary of group comparisons).

There was no difference between the two groups in length of consultation. Furthermore, the ratings of the therapeutic relationship by both the patient and the psychiatrist following the consultation, as measured using the STAR, were compared between the two groups. There were no significant differences between groups on their ratings of the therapeutic relationship, suggesting that the presence of discussion of psychotic symptoms did not influence the experience of the consultation, in terms of the therapeutic relationship, for either the patient or the psychiatrist.

*3.1.4 Symptoms*

The positive psychotic symptoms discussed fell into the two categories; hallucinations, which were discussed in 53/86 (62%) of the extracts, and delusions, which were discussed in 35/86 (41%) of the extract, with some extracts coded as including discussion of both a hallucination and a delusion. Within the extracts including discussion of hallucinations, 46/53 (87%) referred to auditory hallucinations, 10/53 (19%) referred to visual hallucinations, and 6/53 of these

extracts (11%) included discussion of both.

**Table 4.** Group comparisons of patients whose consultation included discussion of present positive psychotic symptoms versus those that did not.

| | Incl. Discussion | Incl. no Discussion | Difference *p* |
|---|---|---|---|
| **PANSS Total Score** | 68.16 | 52.97 | .000 |
| PANSS positive scale | 18.20 | 11.29 | .000 |
| PANSS negative scale | 14.57 | 12.69 | ns |
| PANSS general psychopathology scale | 33.74 | 26.48 | .000 |
| **STAR Patient Total (0-48)** | 38.04 | 38.96 | ns |
| Positive collaboration (0-24) | 19.41 | 19.90 | ns |
| Positive clinician input (0-12) | 8.48 | 8.73 | ns |
| Non-supportive clinician input (0-12) | 2.30 | 2.17 | ns |
| **STAR Clinician Total (0-48)** | 37.46 | 36.21 | ns |
| Positive collaboration (0-24) | 18.06 | 17.27 | ns |
| Emotional difficulties (0-12) | 2.33 | 2.57 | ns |
| Positive clinician input (0-12) | 9.65 | 9.44 | ns |

**Note:** ns = non-significant at the $p < 0.05$ level.

### *3.2 Qualitative thematic analysis*

A preliminary analysis yielded five main themes, each constructed from a number of sub-themes; 'characteristics of psychotic symptom'; 'explanatory model' for symptom; 'emotional response' to symptom; strategies for 'coping' with symptom; and 'psychiatrist focus' in discussion of the psychotic symptom. The links and relationships between the themes were then defined and a basic model of the findings was developed dividing the themes between two over-arching core themes; 'patient disclosure', and the 'psychiatrist focus'. The core themes, themes and sub-themes are presented in Figure 1, and each core theme, theme and sub-theme is described in the text below with examples from the consultations. (Further examples of quotes illustrating each theme can be found in Appendix C).

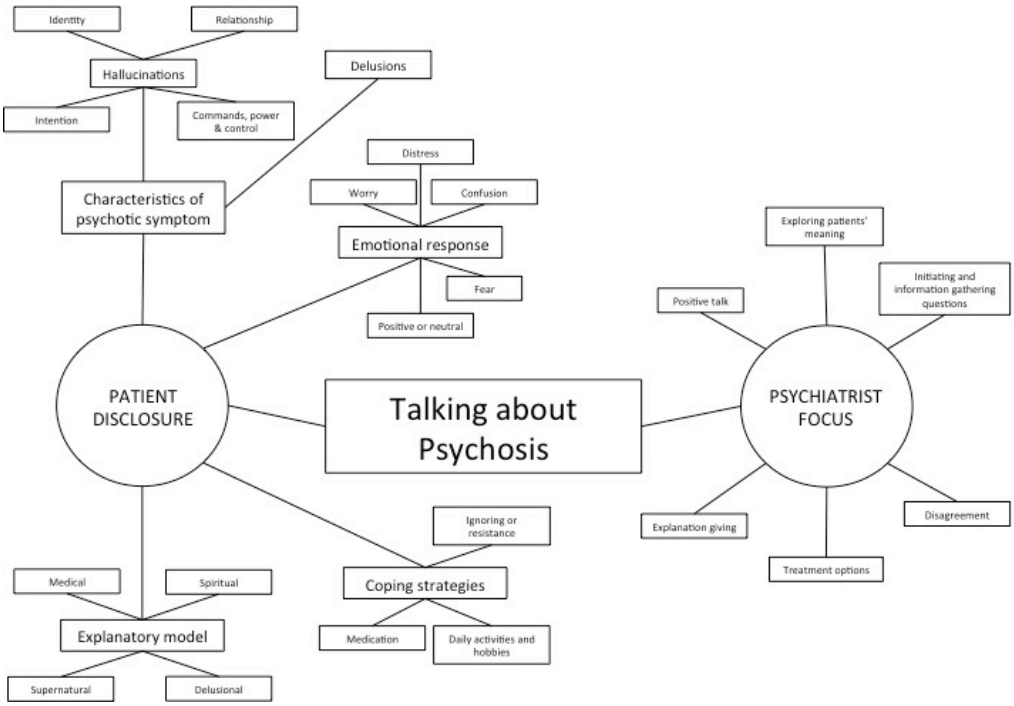


**Figure 1.** Thematic analysis network

*3.2.1 PATIENT DISCLOSURE*

The core theme of patient disclosure incorporated four themes that broadly reflected the experience patients described with regards to their psychotic symptoms. Each of these four themes integrated more specific sub-themes that recurred across the data. In order to get a good sense of the range of psychotic symptoms described, and because the two were experientially quite diverse, the first theme 'characteristics of psychotic symptoms' divides hallucinations and delusions into separate themes. However, the remaining three themes do not consider hallucinations and delusions in separate categories unless stated.

*Characteristics of psychotic symptoms - hallucinations*

The nature and characteristics of individual hallucinations were discussed in 49 of the 53 extracts that included discussion of hallucinations. Discussions included a wide range of information about hallucination characteristics including content, perceptual qualities, frequency, origin, perceived identity, relationship, intention (malevolence or benevolence), and control and power exerted by or over the hallucination. The latter four themes represented the most salient, defined by greater frequency of instances, and are described in detail below.

Identity

In 27 extracts patients discussed the perceived identity of their hallucination. The majority of these cases referred to the identity of voices the patient was hearing and the analysis focuses therefore on auditory hallucinations in this instance. Patients frequently identified their voices as those of their family members including their mother, father, sister, niece, nephew, cousin, uncle, grandmother, brother-in-law or children. In some cases the relation whose voice the patient reported hearing was no longer alive. In most cases when the voice heard was recognised as that of a family member (alive or deceased) the patient acknowledged that the voice was not truly that of the person in question, although their explanations for the cause otherwise were varied.

> *Patient I get very stressed and I go and I might be in the bathroom and I'll think my mum's called me. So I'll say "what's up mum?" and she'll say "I haven't said anything".*
> *Doctor Yeah.*
> *Patient And so I know.*
> *Doctor And occasionally you'd felt that you were hearing your sister's voice as well.*
> *Patient Yes. Well it's always people I recognise. It's like I don't know why but it's like people I recognise have always been females. [Patient 1007, 00:02:25]*

Patients also commonly reported hearing the voice of God or the devil, and both were more likely to be associated with a spiritual or delusional explanation for the voices.

> *Doctor Do you have conversations with God?*
> *Patient Yes. At first it used to be out loud, but now, you know, I don't want to give off that impression of I'm mad. I just think aloud now if you know what I mean?*
> *Doctor You don't talk out loud?*
> *Patient Not anymore.*
> *Doctor And does God talk to you? Do you have conversations?*
> *Patient Yes, through my head here. [Patient 607, 00:16:27]*

In some cases patients were vague about the characteristics and identity of the voices, recognising only the gender of a voice for example, or feeling that the voice was familiar but not being able to identify it.

> *Patient It varies, it can be all different people. Sometimes they tell me to do things.*
> *Doctor So when you say different people can you recognise these voices?*

*Patient Not all of the time. Sometimes it might be somebody I know but not always. [Patient 1204, 00:05:32]*

To some the voices that they heard were unrecognisable, and perceived identities were described in terms such as “spirits”, “dead people”, “shadows” and “a creature”. Anonymous voices sometimes had specific identities such as “an English gentleman” or “a controlling figure inside called Nemesis”.

*Patient Yeah ‘cause it’s not the normal. I call it speaking because it’s not like mine and your voice like a human voice. I don’t know how to describe it. I can only say like a creature. [Patient AP042, 00:02:40]*

Relationship

The relationship a patient had with the voices could often be inferred from their discussions and was coded in 12 extracts. Often patients described negative relationships such as feeling bullied and controlled, hating the voices, feeling criticised and fooled by the voices and believing the voices to be intruding on their privacy.

*Patient Well if I'm making a cup of tea, then I'm thinking that someone's gonna go in and they are counter-reacting me, like trying to bully back on me.*
*Doctor What do you mean?*
*Patient Like, sometimes if I don't do something properly, I'm like superstitious, I think something’s gonna die, and all this, and they sort of refer it back to me that I'm gonna die. They answer me back. [Patient 2602, 00:15:06]*

However, some relationships were reported to be positive, at least in part, with patients describing feeling understood by the voices and protected by them or saying that the voices were happy for or proud of them.

*Patient Well at the moment its sort of like, I suppose you can call it a verbal pat on the back cause they have sort of realised that now I’ve made plans about what I’m going to be doing like with my work and life and stuff like that they are just sort of happy for me I suppose. [Patient AP020, 00:05:08]*

*Patient Oh my God I hate them. And I laugh I really laugh with them. Like I said my brother my brother, my sister, my nephew, my brother-in-law, they say they understand me.*
*Doctor The voices?*
*Patient Yeah they understand me why I talk. And they say “I know”.*
*Doctor It seems that you have lately a good relationship with them.*
*Patient Yeah. I wouldn't say good. I wouldn't say good relationship.*

*Doctor Bearable. [Patient 107, 00:05:16]*

One patient reported laughing with the voices frequently, whereas another said that he was frustrated with the voices because they owed him money. Some patients were reluctant to discuss their relationship with the voices highlighting a possible sense of fear of or control by the voices.

> *Patient At the moment I feel that I should, I am very reluctant to talk about them to anyone, because I think that they should have some privacy and, basically I would like to keep it private if that's okay… I think that's something we have to work out between ourselves, me and the voices, we have to work something out ourselves rather than discussing the voices as that might upset the voices… So I think it's best to leave the voices alone and not to discuss with anyone about the voices and just give them some privacy and they can give me some privacy as well. So that's better if we can get on that way. [Patient 103, 00.17.43]*

Intention

The intention of voices was discussed in 26 extracts, with 5 patients reporting benevolent intentions, 14 reporting malevolent intentions and 7 patients reporting both benevolent and malevolent intentions of the voices. Benevolent voices were described as friendly and reassuring, and sometimes gave commands perceived to be constructive such as clean yourself or do household chores.

> *Doctor So what was the voice telling you?*
> *Patient For example when I am to worry about my situation he tells me not to worry.*
> *Doctor So it's quite a positive voice at the moment?*
> *Patient Yes yes, and he tells me I am going to be fine and reassures me. [Patient AP044, 00:06:44]*

> *Patient Well God might tell me to go to you know to a certain place you know? Or you know that something that will come in to my mind because its something you know like an outing or things like that you know. And there's something good to go to you know, the Lord might say you know go to that sort of thing you know. It's a constructive thing, its not destructive in any way. [Patient AP010, 00:04:52]*

Patients who reported voices with malevolent intent described experiences of hearing negative, abusive and offensive comments, as well as swearing, shouting and screaming.

*Doctor OK. What do you hear?*

*Patient Abuse. It's still abuse, you can't win. I think it's you ca… today it was "I'm going to kill you". [Patient AP042, 00:03:58]*

*Doctor Tell me a bit more about the voices.*
*Patient Well it's all negative. I mean, "I'm not good enough", "I'm not a good person", things like that, it's all negative. It's all negative, so I don't concentrate on listening to them, but I know they're there. [Patient 602, 00:05:14]*

In some cases patients were experiencing both benevolent and malevolent voices, sometimes at the same time, and sometimes in different phases or episodes of their illness.

*Doctor And them, are they threatening in nature? Are they giving you orders or are they belittling you?*
*Patient I am not sure really. They seem to be… sometimes they can be friendly; sometimes they can be overpowering. I am not really sure, but as I said before it's like it's not as often as before so now I have some breathing space whereas before I didn't have any breathing space. [Patient 103, 00:12:07]*

Commands, power and control

Command hallucinations, in which patients reported receiving instructions from the voices, were mentioned in 14 extracts. The concepts of power and control were also raised in 14 extracts with significant overlap with command hallucinations. As a result a sub-theme including all three was created to incorporate these linked concepts. Patients reported receiving positive and negative commands from voices, although negative commands were reported more frequently. Negative commands included instructions to do strange or dangerous actions such as crawl on the floor, or to harm themselves or others.

*Doctor Does it give you instructions as to what to do?*
*Patient When I have been really ill before and I just put myself to bed to get over it because it has been all too much, a voice has come to me, really deep inside like it is all around and all consuming. Like the only message and one voice said to me "commit suicide". [Patient 1204, 00:07:09]*

*Doctor Okay. Do they tell you to hurt yourself or hurt other people?*
*Patient Sometimes. Sometimes they say something but I just ignore them. [Patient 2304, 00:07:36]*

Patients reported finding the commands hard to ignore and sometimes found themselves feeling as though they were being controlled by the voices.

*Doctor Okay, right. And do they, can they control you or take control over you? Can they take control over your body or mind or anything? These voices?*
*Patient Yeah, sometimes, yeah, yeah.*
*Doctor In what sense?*
*Patient In the sense of doing like, if you're washing dishes or something and thing, "pick this up" or "put this down".*
*Doctor Okay, but they can they make you like a zombie, like?*
*Patient Yeah, yeah, they can, yeah, they can. [Patient 1104, 00:04:40]*

*Patient Yeah, I am not really sure whether I should discuss it with you at some point because it's personal. Basically they can be overpowering and I don't think there is a way of coping. I think it's basically the ball's in their court. They can basically… It feels like they are controlling me. [Patient 103, 00:10:57]*

A commonality between these sub-themes, and the way that patients described the characteristics of their hallucinations in general, was the importance of the personal meanings equated to the experiences.

*Characteristics of psychotic symptoms - delusions*

Delusions, in which the patient held a false belief with conviction in spite of evidence to the contrary, were alluded to in 35 of the 86 extracts (41%). Only those delusions identifiable as false beliefs on the basis of either the unrealistic or bizarre content of the belief (e.g. mind reading) or on information disclosed during the consultation (e.g. patient acknowledges no evidence of the delusion beyond a "feeling") were extracted. Although there was much overlap in the categorisation of delusions, broadly speaking the main categories of delusions described by patients included surveillance, persecution, mind reading, thought control, delusions of reference and grandiose delusions.

Twenty-three patients reported delusions involving being under surveillance and/ or persecuted. Surveillance delusions included beliefs that people were watching them in public and listening to their conversations, being bugged, filmed, spied on and followed by a car. In addition persecutory delusions included beliefs of people being out to get them, neighbours poisoning their food, being talked about and attacked in public, and being set-up to go to prison.

*Doctor Do you get the feeling that people are watching you?*
*Patient Sometimes. Quite a lot actually. It's quite scary really.*
*Doctor That some unknown people are trying to harm you in some way?*
*Patient Well yeah. It feels like that.*

*Doctor Do you have ideas as to who these people are?*
*Patient Nope, I feel like I'm being watched. [Patient 1202, 00:07:46]*

*Doctor Okay, alright. And do you ever feel that people are out to get you?*
*Patient Yes.*
*Doctor Out to harm you?*
*Patient Yes.*
*Doctor What makes you think that?*
*Patient What makes me think that? Well it's just the fact that I feel that sometimes people are out to get me.*
*Doctor It's a feeling?*
*Patient It's a sensation, a feeling, of insecurity. [Patient 602, 00:09:07]*

Nine patients held delusions concerning mind reading, whereby they believed that other people could read their mind; however, they did not believe that they themselves had the skill to read the minds of others. This belief caused concern, anxiety and embarrassment for some.

*Patient What is concerning me is that I seem to think people can read me mind you know. It's been a long time this thing has where whatever I'm thinking other people can know. You know like you know if it's like people around me in the neighbourhood and all that they know exactly what I'm thinking. [Patient 1201, 00:02:35]*

Delusions related to thought control were held by nine patients and included beliefs that others were putting thoughts into or taking them away from their mind. Variations included the belief that their emotions were being controlled by others, and a belief that external forces were controlling their behaviour as the result of an alien abduction or possession by the devil.

*Doctor And do you ever believe that people put thoughts into your mind or take thoughts out of your mind?*
*Patient Yes. Yes.*
*Doctor How do they do that?*
*Patient It depends on a topic or subject. You could talk about something but it offends you and it plays on your mind afterwards. Or an aftermath of a result of something that's passed and it doesn't stick in your mind, but something that hurts, does, can play on your mind like. Somebody can say something hurtful -*
*Doctor And then you might -*
*Patient And then I might think about it later, yeah. [Patient 601, 00:27:30]*

Some delusions were referential, in which the patient believed that specific references were being made to them in the media or through other means. Seven

patients described holding referential delusions including receiving messages from famous people through social media (e.g. twitter), receiving messages from the TV to do things, and communicating with celebrities through the TV.

> *Patient Coincidence and serendipity is that the right word? Like a coincidence. For example I'll be thinking about something and then someone on the telly would say that very same thing. I should point out that I'm sane enough to know that it's just coincidence so I step back and think, you know, it's not important. Sometimes when I'm walking down the street I found myself reading people's logos on their shirt or when a van or a car goes by and it's got a logo on the side.*
> *Doctor And what would it say these logos generally?*
> *Patient Just names of companies and stuff like that, but I read them and as I read them it clicks over in my brain how they could relate to me in my life. [Patient 204, 00:04:34]*

A small number of patients had delusions that could be described as grandiose such as the belief that they were Jesus, that they were projecting the reality of the world through their own experiences, that they were king of the world, or that they represented a higher intelligence and had been integrated with the "primitives" (everyone else).

> *Doctor Last time when we met you mentioned that you feel that you are the king.*
> *Patient I do think I'm the king of the world sometimes. I think like… of all the world it's you know what I mean? It's just like it's just a happy thought really in all the hell that I'm in. [Patient 1001, 00:04:56]*

*Explanatory model*

Patients had a variety of ways of explaining the presence of psychotic symptoms both in terms of their long-term origin, and in terms of recent triggers. Although due to the nature of the consultations the explanatory model the patient adhered to was not usually explicitly stated, it could often be inferred by the way the patient referred to their symptoms or answered questions posed by the psychiatrist regarding the "meaning" of their symptoms. Explanations for symptoms were alluded to in 48 of the extracts, and fell broadly into the sub-themes of 'medical', 'spiritual' and 'supernatural' explanations. A further category of 'delusional' was created to incorporate those whose explanations for their symptoms were strongly embedded in their delusional belief system, but did not appear to fall into the categories of spiritual or supernatural.

Medical

In 17 extracts patients alluded to their symptoms as being part of their illness or not being 'real'. These explanations were grouped under the sub-theme of 'medical' explanatory model as they fell inline with the traditional medical model view of psychotic symptoms as symptoms of a neurobiological illness. Patients were sometimes matter of fact about this understanding, whereas others expressed less conviction in this explanation.

> *Patient Well, when I'm in my flat, I think they're coming from outside the flat. Voices outside. But obviously I know, I know they're not. But that's what I think, I think they're coming from outside the flat.*
> *Doctor But you said you know they're not.*
> *Patient Well I know it's part of my illness. [Patient 602, 00:06:50]*

> *Patient Well at first I used to think that I was the Son of God, you know?*
> *Doctor Do you still think you're the Son of God?*
> *Patient Well, it's pretty impossible, isn't it?*
> *Doctor Sounds like you still believe that to some extent or…?*
> *Patient Well, you have to …there's reality and then there's not reality, you know, so you have to keep it in check, don't you?*
> *Doctor Okay.*
> *Patient You know, regardless of the thoughts, you know.*
> *Doctor So you can kind of take a step back…*
> *Patient Well, you have to otherwise you'll go crazy, you know what I mean? [Patient 607, 00:09:58]*

Spiritual

In 13 instances patients alluded to an understanding of their symptoms that was grounded in a spiritual or religious explanatory model such as hearing the voice of God, or being possessed by the devil.

> *Doctor Who would be doing that?*
> *Patient God.*
> *Doctor God. Apart from God can anyone else do that?*
> *Patient Well, there's of course the devil. But you don't really wanna be acting for the devil, do you? [Patient 607, 00:14:32]*

> *Patient I just felt that I was under possession and I have said it before, this is what I felt.*
> *Doctor So you don't – and that's something distinctive from mental illness?*
> *Patient It's totally connected because.*
> *Doctor It's connected?*
> *Patient I know you may not believe in the demons and people being possessed by evil spirits but I, I mean from what I've seen of things, I think it's I think they're real. I think they are real and they do possess*

*people when they – and when – the Doctor can't see the spirit but will see the problem the spirit is bringing like, the spirit will be bringing schizophrenia to the person. The, how can you describe it? The root of the problem is the evil spirit. The evil spirit, the problem that the spirit is bring to that person is schizophrenia. [Patient AP042, 00:20:50]*

Supernatural

Eight patients referred to supernatural causes for their symptoms including hearing the voices of dead people, being from an alien species, or other people being alien species.

*Patient I still keep hearing the spirits. I still like you know? I know they're there 'cause they're there all the time the spirits you know.*
*Doctor When you say spirits can you be er you-*
*Patient Dead people, spiritual people. [Patient 301, 00:04:11]*

*Patient I can't class myself as a human being. I don't put myself as a human being.*
*Doctor What do you mean by that? That can mean many things to me.*
*Patient Yeah.*
*Doctor But I'm not sure what you mean, do you mean you're not from this world?*
*Patient Yeah. I believe, you know, that's what I believe. Whether you think I'm mad or not but that is my belief.*
*Doctor Do you mean in the sort of way that you literally came from space or that there is a soul of a spa', some body from another world in you or do you, do you. How does it work?*
*Patient Well, going back in the past, in the sixties I was followed by a space ship. I was on me bike and my mother will tell you and I believe they took control of me. [Patient AP013, 00:07:00]*

*Delusional*

A number of patients (16) explained their symptoms in a way that fitted with their delusional beliefs, in particular those that were persecutory. For example, some patients stated that their symptoms were being given to them as a form of torture or punishment for previous wrongs, but did not or could not specify who might be responsible for doing this.

*Doctor If you had to explain to somebody why you think you can hear a voice like that, what do you think might be the reason?*
*Patient I think it's sort of, someone putting thoughts into me head.*
*Doctor Somebody puts thoughts into your head. Who do you think might want to do that?*
*Patient I dunno. [Patient 2103, 00:02:49]*

*Doctor So these messages that you are getting off the telly and the radio, where are they coming from?*
*Patient Well them people are like eh the enemy.*
*Doctor Why?*
*Patient Because they say I done bad things.*
*Doctor And how do you know it's not your mind or your own thoughts causing them?*
*Patient Because I can hear them from my ears. [Patient AP051, 00:07:30]*

*Emotional response*

In 40 (47%) of the 86 extracts the patient referred to their emotional response to the psychotic symptoms, and three quarters (31) of these referred to negative rather than positive or neutral emotions. Patients commonly reported feeling distressed in response to their symptoms. Worry, fear, and confusion were also commonly described as well as some positive and neutral feelings.

Distress

Twenty-one patients expressed feelings of distress in response to their symptoms including feeling upset or depressed, overwhelmed, demoralised, vulnerable or hopeless.

*Doctor And how does that make you feel?*
*Patient Demoralised. Well I sometimes feel I'm losing my privacy, my confidentiality. That's what I find upsetting. [Patient 602, 00:07:27]*

*Patient Honest, I'm not lying to you, I don't know what to do about it. I don't feel I'm getting any better and I'm often sitting, coming into the Southwest for all these years now, and I don't know how to, they can't get voices out your head. [Patient 702, 00:05:41]*

Worry

Worry and symptoms of anxiety were also described by patients in 10 extracts in response to their symptoms, particularly in relation to being in public places or social situations where other people might notice that something is wrong or make a judgement about the way they are acting.

*Patient I just, I can't like control like my mind anymore, and I get panic attacks, and I, I think that people are talking to me all the time, or most of the time. [Patient 2602, 00:10:54]*

Fear

Ten patients reported being fearful in response to or as a consequence of their symptoms, particularly those patients who described paranoid delusions involving other people and those who experienced voices with perceived malevolent intent.

> *Doctor So the voices tell you they're going to hurt you, and then what do you think?*
> *Patient I get fri- I get frightened. [Patient 2602, 00:17:25]*

Confusion

A small number of patients (6) expressed confusion relating to their symptoms, as they were unable to satisfactorily explain to themselves the origin of these symptoms.

> *Patient I don't know, I don't know.*
> *Doctor At the moment you feel that what you think is your own thoughts?*
> *Patient No, no.*
> *Doctor Whose thoughts are they?*
> *Patient I don't know. Sometimes they come from me, sometimes they call my name. When I look out, when I sit I don't see anybody. [Patient 701, 00:06:38]*

> *Patient Because it's so overwhelming that you just wonder where could it be coming from? What kind of environment could it be coming from, and what is all – what does it mean? And you are very preoccupied with all those things, you know, on a daily basis. [Patient 1103, 00:13:47]*

Furthermore, some patients reported being confused about how they should best respond to their symptoms

> *Patient And then I'm conflicting myself and I think to myself do I listen to this one? Do I listen to this one or do I listen to myself and then – I don't know where I am, if I'm coming, going or anything. (Patient 2404, 00:11:21)*

Positive or neutral feelings

Although not all experiences of psychotic symptoms were presented as negative experiences it was rare for individuals to explicitly describe positive emotions in response to their symptoms with only two people mentioning feelings of happiness, and in these cases referring to their emotional response to pleasant psychotic experiences in the context of more typically negative ones. More frequently (7)

patients described neutral feelings, having become accustomed to their symptoms over time.

> *Doctor Is it frightening?*
> *Patient At the start it was but then not really, not after a while. Just it's you get used to it. You think, you know what I mean, just another day. [Patient 1001, 00:03:19]*

Therefore the overwhelming emotional response to psychotic symptoms expressed by patients was negative.

*Coping strategies*

In 36 instances patients made reference to coping strategies that they used in order to manage their psychotic symptoms. In most cases these coping strategies were in response to hallucinations, although some were utilised in response to recognised thinking patterns including paranoid thoughts. Most commonly used coping strategies were grouped into the sub-themes of 'ignoring or resistance', 'daily activities and hobbies' and 'medication'.

Ignoring or resistance

The most frequent strategy for coping with psychotic symptoms, cited in 14 extracts, was to ignore or block them out. In some cases this was combined with active resistance such as answering back to voices.

> *Patient I just ignore them.*
> *Doctor Can you stop them by ignoring them or are they still there?*
> *Patient I think you do, yeah. When I just tell them to "shut up" in my own head they kind of stop, yeah. [Patient 201, 00:03:19]*

> *Patient And I try to fight them off, like I tell them to go away. [Patient 2602, 00:17:33]*

Daily activities and hobbies

Daily activities or hobbies were also frequently mentioned (13) as coping strategies. These included having a bath, watching TV, listening to music, speaking to people, going to bed, getting plenty of rest, fresh air, exercise, attending groups, smoking, and drinking alcohol. These activities were generally acknowledged to work via the process of distraction or relaxation or both and were usually presented as being helpful.

*Doctor What techniques do you do, how do you manage to do it?*
*Patient Well I go out meeting people in my walking group. And, listen to the radio.*
*Doctor Yeah, and does it work?*
*Patient Seems to work, yes, seems to take my mind off them. [Patient 602, 00:05:35]*

*Patient You've asked me before and I do see the odd shadow and something, you know, what I mean? But funnily enough if I take a bath it stops everything. [Patient 606, 00:25:45]*

*Patient I go to classes trying to learn something. I do art and stuff and with the other people it seems when I'm mixing with people it doesn't seem to happen as much. So it's more a solitary thing really. Maybe cause I'm with other people, I'm working on the computer or a drawing or something I'm distracted. [Patient 204, 00:06:58]*

Some of these self-generated strategies were thought to be effective in the short-term, but had negative long-term consequences, such as drinking alcohol and responding to voices with violence.

*Doctor Is that what made you smash your telly last time?*
*Patient Yeah all the time they annoy me they keep on and on and I get frustrated, and they torment me and when I break it I feel better. And then after, I regret it a couple of hours later. I thought "what the hell have I done?" you know? [Patient AP051, 00:07:04]*

Medication

Seven patients acknowledged benefits of medication as a way to reduce their psychotic symptoms.

*Doctor What makes the voices go away?*
*Patient The pills. Well they don't make them go away completely. Just a little bit.*
*Doctor But it makes it a little bit better. [Patient 1202, 00:04:55]*

### *3.2.2 PSYCHIATRIST FOCUS*

The core-theme of psychiatrist focus incorporates a number of salient themes and broadly represents the focus of the psychiatrist and their engagement in discussion of positive psychotic symptoms. Given the nature of thematic analysis, which focuses on explicit themes in the data, it was not appropriate to look more closely at processes in communication that might more comprehensively indicate psychiatrist engagement. However, although this analysis is not exhaustive, it is still of interest and relevance to present the themes that arose from the data as representative of

the perspective of the psychiatrist during consultations.

Initiating and information-gathering questions

Psychiatrists initiated discussion of psychotic symptoms in 52 of the 86 extracts (60%). The topic was almost always introduced with a question, and these initiating questions could broadly be arranged into four categories. Most frequently (24/52) the question made a direct reference to a specific symptom, for example "do you hear any voices?" or "do you feel that people want to hurt you?". In 17/52 extracts psychiatrists initiated the discussion by making reference to information given by the patient in a previous consultation, e.g. "you told me in the previous appointment that you were hearing some voices?". In seven extracts the psychiatrist used a broad and general question such as "have you experienced any unusual feelings?", and in a minority of cases (4/52) psychiatrists posed a question about a specific symptom as part of a structured assessment "just routine questions that we ask in general; any unusual voices when there is no one around?".

In terms of information-gathering questions more broadly, 68 of 86 extracts (79%) were coded with 'exploration', signifying any engagement by the psychiatrist in the discussion of psychotic symptoms, namely by asking information-gathering questions. A large proportion of psychiatrist talk was made up of information-gathering questions, but some questions stood out as more frequent such as questions referring to the spatial origin and frequency of voices for those patients experiencing auditory hallucinations. For example, psychiatrists frequently asked patients to specify whether the voices were inside or outside of their head, or inside or outside of the room with them.

> *Doctor Where does it come from? Is it within your head or do you hear it from outside?*
> *Patient It is like the perception or conception of God, but it is not God.*
> *Doctor But do you hear it through your ears?*
> *Patient I hear it and feel it at the same time.*
> *Doctor Yeah, do you hear it through your ears? [Patient 1204, 00:05:39]*

Other frequent questions posed by psychiatrists in relation to voices included the precise frequency of the voices, and whether or not the voices provided a running commentary on the patient's behaviour. The patients mostly denied this experience.

*Doctor Do they ever describe what you're actually doing though, at the time that you're doing it? So if you were making a cup of tea, do they ever say things like, "oh look at him making a cup of tea"?*
*Patient No, nothing like that. [Patient 2602, 00:15:29]*

In discussions about both persecutory delusions and command hallucinations psychiatrists tended to ask more frequent questions relating to the potential risk posed by the patient, either to themselves or others.

*Doctor Have you ever harmed anyone before?*
*Patient No. I've never harmed anyone.*
*Doctor Sorry that's just… I need to ask. That's part of my assessment.*
*Patient I haven't. [Patient 607, 00:08:29]*

Exploring patients' meaning

In 29 of the 86 extracts psychiatrists explored the meaning patients attributed to their psychotic experience. Two types of questions or statements were particularly prominent in discussions exploring symptom meaning including open questions and closed questions that held an explicit or implicit explanation. Open questions were asked frequently when a psychiatrist explored meaning and were broad, non-leading, and gave no indication of the psychiatrist's viewpoint.

*Doctor And how do you explain it to yourself, when you hear the voice? [Patient 2103, 00:02:39]*

Closed questions including explicit suggestion of an explanation for the symptom were also very common.

*Doctor What I mean is, is it possible that you could be wrong about this, that there is no force out there. That this is just something in your mind possibly? That you've been mistaken. Could it have been part of a mental illness such as schizophrenia? Possibly? [Patient 606, 00:13:39]*

*Doctor Do you think that your mind's playing tricks on you? [Patient 1102, 00:12:57]*

Similarly, some of the questions asked by psychiatrists in response to expressions by patients about the meaning they had equated to their symptom held an implicit disagreement or suggestion of an alternative viewpoint. Such questions often included words such as "really", "actually" and "literally", e.g. "do you actually think that?".

*Doctor Do you really think that or is it just…? But it can't be possible can it? [Patient AP015, 00:04:19]*

*Doctor Are you joking? Or you really think that this person, that voice owes you money? [Patient 107, 00:15:25]*

Both types of open and closed questions tended to occur in extracts in combination whereby the psychiatrist would ask an open question about meaning followed by a closed question including an explicit and/ or implicit suggestion of another, usually medical, explanation.

*Doctor So these messages that you are getting off the telly and the radio where are they coming from?*
*Patient Well them people are like eh the enemy…*
*Doctor And how do you know it's not your mind or your own thoughts causing them? … How do you know it's not a hallucination that you are listening to? [Patient AP051, 00:07:30]*

Explanation giving

Psychiatrists gave explicit explanations for psychotic symptoms in eight of the 86 extracts. Two of these instances of explanation giving occurred in response to a question asked by the patient, whereas the others were spontaneous explanations given inline with the general discussion around symptoms. All explanations were characterised by cautious language such as "I believe", "I think", and "I suppose", as well as conditional statements such as "it might be" or "could be". In some cases the psychiatrist also questioned the patient on their understanding of and agreement with the explanation given. Patients' responses varied from reporting being reassured by the explanation to changing the topic or conjecturing on the origin of their mental illness suggesting agreement with the explanation.

*Doctor I quite often hear people say that they can hear voices when they come and see me here in the clinic, and I suppose my theory about it is that it's to do with an illness that they have. It's part of, it's a symptom of an illness. And their mind is playing tricks on them. Do you think that might be the case with you?*
*Patient Yeah. [Patient 2103, 00:03:45]*

*Doctor Yeah well I'm wondering whether these… I'm just increasing the medicines to try and dampen down these things, these voices that you know you feel are coming from the real world. I mean I think they might be part of your illness to be honest. It's like a symptom like a hallucination that people get and they can be really real sometimes, really quite freaky. [AP051, 00:09:56]*

Positive talk

The sub-theme 'positive talk' encapsulated empathy, positive statements, reassurance and normalising. 34 of 86 extracts (40%) were coded with one or more of empathic statements (17), positive statements (17), and reassurance or normalising (8) by the psychiatrist. Empathy most often took the form of a single statement referring to the patient's possible emotional response to the psychotic symptom in question.

> *Doctor Okay. Alright. It must be very distressing.*
> *Patient It is. [Patient 602, 00:08:33]*

> *Doctor Some of these experiences especially about that must be very disturbing. [Patient 1001, 00:06:42]*

Positive statements were most commonly employed in giving positive feedback to a patient with regards to efforts they were making, either in relation to adherence to their treatment, or to progress made in terms of an improvement in their mental health.

> *Doctor I think that's an excellent therapy in itself. I think it's an excellent treatment doing something … you did something that helps. You should continue doing that. [Patient 606, 00:26:02]*

> *Doctor That's very good. So you put the radio on, and that has prevented these voices okay. That's a good way of distracting yourself. [Patient 701, 00:07:46]*

> *Doctor That is good. Well the most important part of this is so that you are getting better and that is what we want to achieve. And that the periods when you are not hearing these voices are increasing and that is what we wanted. So you are making good progress in terms of your mental health. [Patient 2502, 00:05:58]*

Less frequently than empathy or positive statements, reassurance or normalisation was given to patients in response to descriptions of their symptoms or questions about the symptoms. Reassurance and normalisation invariably took the form of generalising the experience to the broader population using phrases such as "some people experience…".

> *Doctor Because that can be a time when a lot of people experience things; seeing things, hearing things. When people are just at that point of going to sleep. It's quite common and the other time is when people are just waking up. [Patient 204, 00:15:19]*

*Doctor Many people find difficult to explain things like voices. [Patient AP021, 00:08:15]*

Disagreement

Disagreement about symptoms or diagnosis was coded in eight extracts, all of which related to delusional beliefs rather than hallucinations. The result of disagreement varied between a change of topic, a shift to a less oppositional or explicit position by either the psychiatrist or the patient, and an explicit statement of disagreement. The disagreements coded in these data extracts were not dramatic or lasting and did not result in a breakdown in communication within the consultations.

*Doctor Do you really think that or is it just…?*
*Patient Its like the you know its like sometimes…*
*Doctor But it can't be possible can it?*
*Patient In the telly?*
*Doctor Yeah, it's not it doesn't happen in real life does it?*
*Patient What do you mean by "real life"?*
*Doctor There are no messages coming from the television to people are there?*
*Patient Oh no no. I'm not saying somebody saying something, nobody saying something in the telly but the way I feel…*
*Doctor Okay.*
*Patient It's just something telling me you know? [Patient AP015, 00:04:20]*

*Patient (Laughs) I know it sounds like a load of garbage but…*
*Doctor It probably is, but I mean you know, that's you know we just have different views of these things.*
*Patient I know it's quite it's quite different yeah.*
*Doctor Yeah.*
*Patient I was just saying what I think. [Patient AP042, 00:22:46]*

Treatment options

Treatment options were referred to by psychiatrists in 28 of the 86 extracts. The majority of these references (22/28) were to medication. When psychiatrists mentioned medication in relation to psychotic symptoms common questions posed included whether or not the patient was taking the medication, whether the patient felt the medication had any benefits, and recapping on the current dosage and pattern of taking medication (e.g. time of day). In some consultations psychiatrists asked the patient whether they wanted to change their dosage or medication, or whether a previous change had made a difference, and in others psychiatrists were more didactic in recommending and making changes to the prescription.

Psychiatrists also made recommendations about taking medication regularly and how and when best to take it.

> *Doctor And you increased the Olanzapine last time partly also with regards to these thoughts of being spied on or being followed.*
> *Patient Yes.*
> *Doctor Did it make any difference at all?*
> *Patient I think it has made a difference. [Patient 1106, 00:07:13]*

> *Doctor Well, like I said the medication Dr [Name] gave to you needs to take some time to work, we'll kind of monitor things as it goes by. And, what I'm looking for is an increase in the periods when you feel still unwell within yourself. Now, if that doesn't increase then I'm happy with that progress. Okay, I will continue to monitor you in the clinic. [Patient 2501, 00:11:57]*

In a handful of extracts psychiatrists referred to other potential treatment options for psychotic symptoms including psychological therapy (3), daytime activities (3) and general healthy living (1).

> *Doctor We give you medication. We give you the Clopixol to help deal with the voices.*
> *Patient Yeah.*
> *Doctor Sometimes people also find it useful to talk to someone about what they hear. [Patient 2601, 00:04:00]*

## 4 DISCUSSION

### *4.1 Summary of results*

In summary, results from the descriptive quantitative analyses indicated that of 143 routine psychiatric consultations 65 contained at least one discussion of a present positive psychotic symptom, and 78 did not. This was inline with the level of positive psychotic symptoms patients were experiencing at the time according to an independent clinical assessment of psychotic symptoms. The majority of patients and psychiatrists in the study were male, and patients tended to be single and unemployed. Patients were ethnically diverse corresponding to the ethnic mix within the local population of East London. The majority of positive psychotic symptoms discussed in the consultations were hallucinations (most of which were auditory), followed in frequency by discussions of delusions. Psychiatrists were more likely than patients to initiate and end discussions of positive psychotic symptoms demonstrating the role of the psychiatrist in leading the consultation. Psychiatrists commonly ended a discussion of psychotic symptoms even when the patient had initiated the topic, whereas patients were very unlikely to end the discussion when the psychiatrist had initiated it, a finding that can be interpreted to reflect a power differential in the consultation. Inclusion of discussion of psychotic symptoms did not affect patient or psychiatrist ratings of the therapeutic relationship following the consultation or increase consultation time compared with having no discussion of psychotic symptoms. Discussions of psychotic symptoms took up 16% of the consultation time on average.

A thematic analysis exploring 'talking about psychosis' yielded two core themes containing themes and sub-themes. The core theme of 'patient disclosure' comprised 'characteristics of psychotic symptoms', 'emotional response' to psychotic symptoms, 'explanatory model' for psychotic symptoms and 'coping strategies' for psychotic symptoms. Each of these themes contained sub-themes that, in combination, represented the pattern of patient disclosure of their experience of positive psychotic symptoms. In summary, patients described idiosyncratic characteristics of psychotic symptoms that related to the personal meaning of the symptom to them, such as their relationship with a hallucination, rather than perceptual or temporal characteristics. The emotions that patients experienced in relation to psychotic symptoms were in general negative and passive, including fear, worry and distress. Patients disclosed a range of models for

explaining their symptoms included a traditional medical model, but also including spiritual or supernatural explanations, and explanations that were embedded within other delusional ideas. Patients also discussed how they coped with psychotic experiences, and frequently cited strategies that were simple and accessible and did not rely on financial, social or professional support, for example going for a walk or listening to music.

The second core theme elicited by the thematic analysis, 'psychiatrist focus', incorporated themes that summarised the responses of psychiatrists in discussion with patients about psychotic symptoms. These themes included 'initiating and information gathering questions', 'exploring patients' meaning', 'explanation giving', 'positive talk', 'disagreement' and 'treatment options'. The majority of input from psychiatrists during the discussions fell into the category of information gathering questions, and resulted in the psychiatrist leading the direction of the discussion. In some cases the questions asked by psychiatrists focused on characteristics of symptoms that were incongruent to those focused on by patients, for example spatial origin or frequency of a hallucination. Psychiatrists openly explored the meaning that patients equated to symptoms in some cases, but also frequently gave implicit or explicit suggestions about the meaning when asking the patient for their own view, thereby possibly influencing the patient's response. At times when psychiatrists gave explicit explanations for symptoms, inline with the medical model explanation, these were presented in a tentative and sensitive manner, and did not result in opposition or open disagreement with the patient. The theme of positive talk included empathy, positive statements and reassurance to patients about psychotic symptoms and occurred in over one-third of the extracts, but often occurred only once in discussion in contrast to other processes such as information gathering questions. Although rare, explicit disagreement did occur in the consultations, but did not result in a breakdown in communication or noticeable impairment of the therapeutic relationship. When psychiatrists talked about treatment options for symptoms they tended to focus on medication, but with some mention of alternative options such as daytime activities. This was again juxtaposed with patients' disclosures of coping strategies, which mostly focused on daytime activities and rarely mentioned medication.

### *4.2 Talking about psychosis - patient disclosure*

Patients wanted to talk about psychotic symptoms in psychiatric consultations as evidenced by 86 instances of discussion of different positive psychotic symptoms in 65 of 143 consultations. Patients experiencing greater levels of positive psychotic symptoms were more likely to discuss psychotic symptoms during the consultation. Over a third of the discussions were initiated by the patient, which is striking in the context of consultations being predominantly psychiatrist led. This finding is in keeping with the assertions of psychological approaches to the treatment of psychosis (e.g. Chadwick, Birchwood & Trower, 1996; Kingdon & Turkington, 1991), as well as support groups and other forums that provide opportunities for people to share and explore the content and personal meaning of their psychotic symptoms (Escher & Romme, 2012) that patients wish to talk about their psychotic symptoms. It provides further support for the findings of McCabe and colleagues (2002) who showed that patients continued to try to discuss the content and emotional consequences of their psychotic symptoms with their psychiatrist, even when their attempts were met with resistance.

*Characteristics of psychotic symptoms - hallucinations*

When patients talked about hallucinations they spontaneously described features that demonstrated their personal meaning. Auditory hallucinations, or voices, typically had been ascribed identities such as family members or God, and had been attributed with benevolent or malevolent intentions by the patient. In some cases patients believed that the voices held power or control over them and patients typically described voices as if they were sentient beings with deliberate intent. The personal meaning of hallucinations to patients is a cornerstone of psychological models of psychosis such as the CBT model. According to this model the interpretation of the psychotic symptom, for example the identity and intentions attributed to it, rather than the symptom itself is crucial in determining the level of distress experienced by the patient in response to the symptom. As well as acknowledging the significance of the attributed identity and intention of the voices, Chadwick and Birchwood (1994) particularly emphasise the importance of power or omnipotence of voices. The concepts of power and control arose in patient descriptions of their voices in this study, particularly in relation to command hallucinations, but were not evident in all patients' descriptions of their symptoms. In keeping with this finding cognitive therapy for command hallucinations places particular emphasis on perceived power and superiority of voices and has been

found to reduce patients' degree of conviction in the power or superiority of the voice as well reducing their compliance behaviour in response to commands (Trower et al., 2004). More recent psychological models of psychotic symptoms have begun to emphasise the importance of relational aspects of meaning constructed around psychotic symptoms (e.g. Hayward et al., 2013). The finding in the current study that a number of patients identified the voices they could hear as family members with whom they likely had (or had had in the past) a real relationship supports the importance of this aspect of the experience. In addition, patients frequently alluded to the relationship that they had with the hallucinations, suggesting for example that they could be bullying or protective. Parallels have been drawn between interpretations of voices and representations of social relationships in reality (Birchwood et al., 2004; Hayward, 2003) leading to psychological therapies that aim to alter or attenuate a patient's relationship with the voices (e.g. Chadwick, 2006; Hayward et al., 2009). Although the current study was not conducted in a psychotherapy setting, and was naturalistic in design rather than prescriptive in terms of the topics raised, the finding that the features of hallucinations described by patients bear close relation to those characteristics stressed by psychological models provides further support for the appropriateness and relevance of these models of psychosis. Furthermore, the complex and rich nature of the patients' constructed meaning of hallucinations, and the likely links with their own personal relationships and experiences, give further support to the premise that psychotic symptoms are by no means 'ununderstandable' but rather that they are closely linked and associated with the patient's experiences of life in general.

*Characteristics of psychotic symptoms - delusions*

Patients described a variety of delusional beliefs, including those of surveillance, persecution, mind reading, thought control, reference and grandiosity. Although it is likely that patients had encountered disbelief from others and resistance to discussion of their delusional beliefs in the past, including from their psychiatrists possibly, this did not inhibit a number of patients from discussing these beliefs in the consultation. This phenomenon may highlight the desire of patients to have further discussions about their delusions. In the past clinicians were recommended not to discuss the content of paranoid thoughts with their patients, for example in the textbook 'Clinical Psychiatry' discussion of paranoia is considered to be "a waste of time" to be avoided (p.280, Mayer-Gross, Slater & Roth, 1954). However, delusional

beliefs are no longer considered to be exclusively present in those with severe mental illness but are also commonly recognised in the typical population (Freeman, 2006). In addition psychological therapies have recognised the importance of the content and meaning of delusional beliefs, as well as the distress that they cause, and acknowledge the need that patients may have for space to talk about and explore their beliefs and the consequences of these (Freeman & Garety, 2006).

One feature of analysing the data was that it was difficult at times to establish whether the patient was discussing a delusion or a real situation. This difficulty was particularly prominent when a delusion involved paranoia about other people (e.g. neighbours), or when alleging historical maltreatment. For the purposes of the study where there was doubt about the presence of a delusion it was not coded as a psychotic symptom. However, by actively searching for all instances of discussions of psychotic symptom in the data, every ambiguous experience described by the patient was initially considered as a possible symptom. This experience mirrors an issue that psychiatrists have in their clinical practice where by they are unable in many cases to establish the veracity of a patient's account of a situation. Knowing that a patient experiences psychosis may increase the likelihood of pathologising a real experience as a delusion, and may result in a failure to acknowledge actual situations, such as victimisation at work or persecution by neighbours. The act of searching for psychotic symptom discussions in the data is similar to the goals of psychiatrists in terms of establishing the presence of psychotic symptoms for diagnostic and treatment purposes. However, simply establishing the presence or absence of a delusion could be unsatisfactory from the perspective of the patient who is likely to be experiencing distress regardless of whether their situation is real or perceived. Psychological models regard distress itself as a meaningful and relevant measure of functioning and outcome. Given the potential difficulty faced by psychiatrists in identifying the presence of delusions, a better construct to focus on might instead be the distress caused by the belief and the impact of that on the life of their patient (Chadwick, Birchwood & Trower, 1996).

*Explanatory models*

As well as constructing idiosyncratic meanings at the level of the symptoms, such as the identity of a voice, patients had also formed more global understandings of their symptoms in the form of explanatory models. Although these explanations were not

necessarily explicitly described, patients often spontaneously made reference to beliefs that implicitly revealed how they understood the presence of their psychotic symptoms. It is of interest that, of those patients who alluded to an explanatory model for their psychotic symptoms, many were incongruent with the medical model, instead referring to spiritual, supernatural or other explanations for their symptoms. Although this lack of 'insight', as it might be referred to in psychiatric terms, is a common feature of psychosis, it is nevertheless of interest that a number of patients were expressing views that were in opposition to those that they either knew, or likely assumed, were held by their psychiatrist and the broader health system within which they were being treated. This could represent a number of things including a strong belief in their own explanation, dissatisfaction with the medical model referred to by psychiatrists, or a wish to further discuss explanations for their psychotic symptoms. The explanation that a patient holds for their psychotic symptoms is likely to affect their responses to the symptoms themselves, as well as their treatment preferences and the way that they describe their symptoms. Little research has explored how explanatory models might impact treatment outcomes although there is evidence that explanatory models held by patients differ according to cultural group (McCabe & Priebe, 2004), and that dissonance between the patients' and professionals' explanatory models may reduce treatment satisfaction and therapeutic alliance (Callan & Littlewood, 1998; McCabe & Priebe, 2004). In medicine the current dominant biological explanations pay little heed to the meaning of psychotic symptoms for each individual, and patients may find it difficult to accept an explanation for their symptoms that does not explain the personal nature of their experiences (e.g. hearing the voice of a deceased parent). In the current study, although it can be assumed that patients' non-medical explanations for psychotic symptoms were in opposition to those of the psychiatrist, this rarely resulted in explicit disagreement in the consultation; however, this is not to say that discord was not apparent at more subtle levels. In any case, it is possible to interpret as positive the fact that patients felt comfortable enough and able to express an opinion that opposed that of the 'system'.

*Emotional response*

When patients described or alluded to their emotional response to psychotic symptoms they most frequently referred to negative emotions, with some patients also indicating feelings of neutrality. Positive emotions such as happiness were very

rarely described by patients in relation to their psychotic symptoms. Distress in response to psychotic symptoms is widely acknowledged in psychological models of psychosis and reducing distress, rather than symptoms, is the target of psychological treatments developed on the basis of these models (e.g. Chadwick, Birchwood & Trower, 1996; Kingdon & Turkington, 1991). However, psychiatric models of psychosis do not typically measure or target distress instead focusing on the presence or absence of symptoms as an objective of treatment. Of course, arguably this focus is not wrong as with the removal of symptoms comes the removal of negative emotions caused by them; however, this approach does not provide guidance for how to work with people for whom psychotic symptoms are resistant to treatment and thus cannot be removed. In addition the emotional consequences of psychotic symptoms for patients are salient, as evidenced by them raising them frequently in psychiatric consultations.

The negative emotional responses reported by patients tended to be passive, highlighting the patient's sense of being in a position of vulnerability. Only one patient mentioned feeling angry in response to his symptoms with more common responses including worry or confusion. This is interesting when considered in the context of broadly held stereotypes of psychotic patients being angry, aggressive and violent. Although anger is not necessary in order for an individual to be aggressive or violent, it is often associated with these acts. The lack of anger in contrast with higher levels of more passive negative emotions reported by patients might support some arguments that patients with psychosis are more vulnerable to being the victims of violence than the perpetrator (e.g. Chapple et al., 2004), though equally it might reflect what is disclosed by patients within the context of a psychiatric consultation.

Emotional distress is the foundation of a number of mental health problems including mood disorders and in these cases emotion is key to both the diagnosis and treatment of these illnesses. Traditionally psychotic illnesses have been separated from affective illnesses in this regard (e.g. Jaspers, 1963); however research is now indicating a close and bidirectional relationship between emotion and psychotic symptoms in that emotion contributes to the formation and maintenance of psychotic symptoms, and psychotic symptoms result in significant emotional consequences for patients (Freeman & Garety, 2003). Although psychotic

illnesses are increasingly being linked with emotional disturbance, with co-morbid mood disorders being common (Buckley et al., 2009), there is still not much acknowledgement of emotion in the psychiatric care of people with psychosis. That patients in the current sample were discussing the emotional consequences of symptoms, and that these were almost always negative, implies that the patient's emotional response to psychotic symptoms is an important feature that should not be overlooked by psychiatrists.

*Coping strategies*

Coping strategies were most commonly cited by patients in relation to hallucinations rather than delusions, possibly due to hallucinations being more tangible and recognisable than delusions and therefore more quantifiable in terms of the efficacy of coping strategies. On the whole coping strategies described by patients tended to be easily accessible, non-skilled and either free or cheap activities. They were idiosyncratic and were usually self-generated by patients in response to their symptoms. Although a small number of patients mentioned the benefits of being in company as a way of coping with psychotic symptoms, by way of distraction, not one patient named a close or supportive relationship (e.g. with a relative, partner or friend) when considering what helped them to manage their symptoms. Furthermore, there was no mention of healthcare or other professionals who might be involved in a patient's care. This possibly serves to highlight the level of isolation experienced by patients suffering with a psychotic disorder, whether actual or perceived (Hooley, 2010). Due to the fact that a number of patients do not find medication effective or acceptable as a treatment for their psychotic symptoms there is a need to support patients in developing and enhancing coping strategies for dealing with symptoms when they occur. Patients reported using self-generated strategies with some success, and efforts such as these could be easily harnessed and further enhanced in psychiatric practice.

Overall the four themes that arose from patients' descriptions of their psychotic symptoms highlighted the importance of the personal meaning of the symptoms to the patient and their response to the symptoms, both emotional and practical. One question that arises about these findings concerns the extent to which the patients' *descriptions* of their psychotic symptoms during psychiatric consultations can be equated to their actual *experience* of psychotic symptoms. This is a dilemma faced

by any research aiming to explore the experiential nature of certain phenomenon as an individual's personal experience can never be measured completely objectively. Although it can be argued that all contexts would influence descriptions that patients gave at some level, in the current project this question is of particular relevance. It is possible that the context of the psychiatric consultation bore influence on the descriptions patients gave due to factors such as previous experiences of talking about psychotic symptoms to a psychiatrist, the assumptions inherent in psychiatric services about psychosis and effective treatment, and the nature of the psychiatrist – patient relationship. Whilst this is the case, the context of the current study was intentional as it represented an environment of clinical interest. Although there is a growing literature about experiential and salient aspects of psychotic experiences from the perspective of the patient, much less is known about whether these same aspects are relevant in the psychiatric context, both in terms of what patients might wish to disclose and discuss in this context and the approach of psychiatrists in treating patients with psychosis. Therefore, exploring how patients described psychotic symptoms in the context of the psychiatric consultation, as well as the focus of psychiatrists during these discussions were key features of the study. With regards to whether the objective descriptions that patients gave of psychotic symptoms could be equated to their subjective experiences of the symptoms, it appeared that patients were able to express their views, as demonstrated by the degree to which the themes of patients' discussions about psychotic symptoms diverged from those of the psychiatrists. The themes that arose, such as identity, relationship and emotional response, were generated by patients and not by psychiatrists, and were aligned with the themes highlighted as salient features of psychosis according to alternative models (e.g. Chadwick & Birchwood, 1994; Hayward et al., 2009). Furthermore, there was no indication in any of the consultations that the descriptions patients gave of their symptoms were not authentic or valid. There was no reason for patients to misconstrue their experiences, particularly in ways that diverged from the details psychiatrists were asking for. If anything, patients in the current sample were keen to discuss the salient aspects of their own experiences in spite of the departure of their descriptions from the features that psychiatrists showed interest in. Therefore, although the context of this study would inevitably have influenced the disclosures of patients about their psychotic symptoms, the themes that arose from patients'

descriptions of their psychotic experiences appeared to be valid and related to those features highlighted elsewhere in research exploring the experiential nature of psychosis. Furthermore, the fact that these themes arose in the context of the psychiatric consultation points to the relevance of acknowledging these features in this context and their possible importance from the perspective of patients to their psychiatric treatment.

### *4.3 Talking about psychosis - psychiatrist focus*

*Initiating and information-gathering questions*

One role of the psychiatrist in a psychiatric consultation is to assess the patient in order to inform their treatment. The high number of information gathering questions posed by psychiatrists in each consultation reflected this aim. The psychiatrists initiated 60% of the discussions of psychotic symptoms in the current study using a variety of questions either directly or indirectly querying the presence of psychotic symptoms or referring back to past information given by the patient about the presence of psychosis. Psychiatrists tended to ask more questions about hallucinations compared with delusions, possibly because hallucinations are more tangible and quantifiable. Questions about auditory hallucinations were most frequently about topographical aspects of the hallucination such as the location, frequency and volume of voices, although these were not the characteristics of symptoms that patients were inclined to talk about. Other common questions related to the form of the hallucination, for example psychiatrists frequently asked whether or not the voices gave a running commentary on the patient's actions. This experience was frequently denied by patients, and was never spontaneously described by patients as a feature of an auditory hallucination across 46 extracts that included discussion of auditory hallucinations. The question itself refers to a 'first-rank' symptom categorised by Schneider and included in diagnostic criteria for schizophrenia for half a century. The most recent diagnostic criteria have removed the special treatment of first-rank symptoms from diagnosis (DSM-5, APA 2013) as it is now widely recognised that so-called first-rank symptoms do not bear any particular clinical specificity or relevance in the diagnosis of schizophrenia. The current study further demonstrates the lack of relevance of the presence of this form of auditory hallucination compared with any other, and yet psychiatrists repeatedly asked this question in consultations indicating their reliance on diagnostic criteria when exploring the experience of psychosis with patients with

schizophrenia. As well as asking about the perceptual qualities and form of auditory hallucinations other common questions psychiatrists asked about psychotic symptoms evidenced certain colloquial patterns, for example psychiatrists frequently asked “do you get messages from the TV?”, “do you hear voices when there is no one around?”, “any unusual experiences?” and “is your mind playing tricks on you?”. Some of these questions have originated from particular psychiatric assessments of psychosis such as the Structured Clinical Interview for DSM-IV disorders (SCID-CV; First et al., 1996) and appear to have become part of the psychiatrist rhetoric in discussion about psychotic symptoms, whether the patient resonates with these descriptions or not. Although there was nothing wrong with these questions per se it is possible that repetitive and generic questions that are not specific to the patient’s own experiences might become frustrating and result in the patient feeling less well heard or understood, leading to a possible reduction in engagement. Overall, the types of questions asked by psychiatrists aimed to assess the presence and severity of symptoms, rather than to engage with understanding the meaning of the symptoms to the patient and the impact of the symptoms on their lives. This incongruence between psychiatrists’ questions and patients’ descriptions in discussion of psychotic symptoms appears to represent a broader tension between the diagnostic criteria for schizophrenia and the ‘lived experience’ of psychosis. If the focus of the consultation from the perspective of the psychiatrist is at odds with that of the patient from the outset then this is likely to have an impact on the possibility of establishing a truly patient-centred approach in a consultation.

Relating to this point a further interesting contrast was apparent in the data in the balance of questions asked. Although psychiatrist talk was made up almost exclusively of information gathering questions, only 10 instances of patients asking questions about their psychotic symptoms were coded across all of the data extracts. It is to be expected that psychiatrists will ask more questions in a consultation than the patient, but the very low number of questions asked by patients about psychotic symptoms across the whole sample is striking. It might indicate a high level of patient satisfaction with the information provided and their understanding of their psychotic symptoms and related treatment; however, it might also suggest that patients are not empowered or facilitated to ask questions about psychotic symptoms (the incidence of patients asking questions in the rest of

the consultation was not measured and therefore cannot be commented on). The premise of shared-decision making (SDM), an important aspect of patient-centred care, is to collaboratively reach an understanding and make decisions about treatment jointly. It relies on patient participation in consultation, of which asking questions is one part. Some studies encourage the use of aids and preparation prior to a consultation to enable patients to participate in consultations and SDM (O'Conner et al., 2003); however, even without extra resources it is feasible that psychiatrists could further facilitate patient participation, by giving frequent opportunities to ask questions for example. Few studies have explored SDM in psychiatry (Hamann, Leucht & Kissling, 2003), although there is evidence that patients with schizophrenia have a stronger preference to be involved in decisions about their treatment than patients in primary care (Hamann et al., 2005), and that SDM is feasible with this population (Bunn et al., 1997) even when they are acutely unwell (Hamann et al., 2006). In a qualitative study exploring psychiatrists' experiences of sharing decisions with patients about anti-psychotic medication Seale and colleagues (2006) found that psychiatrists were committed to the principles of patient-centred care in general, stating a preference for a co-operative therapeutic alliance with patients. However, the psychiatrists also presented a number of obstacles perceived to stand in the way of delivering this approach such as low patient competence or poor judgement. The utilisation of SDM in clinical practice therefore hinges on the judgement of the clinician as to the appropriateness of this approach for the patient, a view that in the case of patients with psychosis, might be unfairly biased.

In response to patients' descriptions of command hallucinations or their beliefs that voices were powerful or controlling the psychiatrist often prioritised exploration of risk in the discussion. At these times psychiatrists asked questions regarding the patient's safety in relation to their own actions, as well as exploring the potential risk they posed to others. Patients frequently denied that they would hurt themselves or others in spite of the commands, saying instead that they knew right from wrong and had not acted on the commands in the past. It is widely assumed in clinical practice, and by the general public, that the presence of psychosis increases the risk of violence to others; however, research into this phenomenon has presented mixed results, and even in cases where a relationship has been established the impact of other factors in causing or influencing this relationship

have not been satisfactorily explored (Douglas, Guy & Hart, 2009). More convincing is evidence that patients with psychotic disorders are at much greater risk of being the victim of violence (Chapple et al., 2004). Although psychiatrists have a clinical responsibility to consider and explore potential risk with patients, it is possible that they may be over-sensitive to certain aspects of risk, such as a patient's danger to himself or others, over other aspects such as the vulnerability of a patient with psychosis to becoming a victim of violence from others. Furthermore, in these instances the psychiatrists' focus on risk was at the expense of exploring further the personal meaning and emotional consequences of these types of hallucinations with patients. Psychiatrist questions pertaining to the emotional consequences of psychotic symptoms were rare across all extracts. Malevolent command hallucinations are likely to be particularly distressing to patients, and the efforts taken to resist them taxing; therefore, it is of concern that these particular experiences are being overlooked by psychiatrists in favour of considering risk.

*Exploring patients' meaning, explanation giving and disagreement*

In nearly half of the extracts containing discussion of psychotic symptoms psychiatrists asked questions pertaining to the meaning of the symptom from the perspective of the patient. The way in which questions were asked about meaning could imply the different motivations underlying these questions; for example, in some cases psychiatrists asked open questions with no explicit reference to an explanation for the symptoms and no indication of their own personal view suggesting that they were asking the patient to express their own perspective. However, in other examples psychiatrists used closed questions that included an explanation in the question (e.g. "could it have been part of a mental illness such as schizophrenia?"), thereby only asking the patient to accept or deny the explanation suggested without giving their own interpretation. This second type of questioning could serve two functions including expressing the view of the psychiatrist, and establishing the level of 'insight' the patient has regarding their symptoms, i.e. the level to which they accept a medical view that their symptoms are caused by a biological illness. In response to patients' interpretations of their symptoms, where they opposed a medical explanation, some psychiatrists would continue to question the patient, using language suggestive of implicit disagreement with their view, and explicitly suggestive of their own explanation. Often psychiatrists who initially asked open questions about the meaning patients gave to their psychotic experiences

went on to ask more closed or directive questions, and then to become implicitly suggestive or persuasive of the error of the patient's view. The response of patients to psychiatrists' suggestive and leading questions did not indicate a change in their own opinion, highlighting this approach as an ineffective strategy for changing a patient's mind. Psychological models highlight the importance of establishing the meaning that patients equate to their symptoms. In addition, psychological models go further than exposing those meanings, on the premise that these interpretations mediate distress, and work with the patient at the level of their own meaning, emphasising that there is no need for patients to adopt a biological model of illness causation in order to treat them (e.g. Kingdon & Turkington, 1991). However, in the current study some psychiatrists were reluctant to simply accept the opinion of the patient about their symptoms where it differed from their own.

More positive examples of discussions around explanations for psychotic symptoms were those where psychiatrists explicitly named their own position, even if it was in opposition to that of the patient. In these instances psychiatrists used cautious language, demonstrating that their opinion was not necessarily the only one or the correct one, but that it was the one from which they were making decisions about treatment. Even when patients did not share the view of the psychiatrist about the origin of the psychotic symptom, this transparency from the psychiatrist was received positively by patients. The differences in the way that explanations were discussed and given could have implications for the therapeutic relationship and engagement in treatment. Whereas implied and suggestive questions and statements by the psychiatrist about the meaning of symptoms did not serve to facilitate the conversation or change the mind of the patient, more explicit position naming and explanation-giving by the psychiatrist was received with appreciation by patients. McCabe and colleagues (2002) also found that psychiatrists' implicit disagreement with patients about their symptoms, indicated by hesitation, avoidance and laughter, resulted in perseveration by patients in expressing their own opposing view. Interestingly, in the current study where explicit disagreement arose in the consultation this did not result in a breakdown in communication overall, and again patients appeared to appreciate the transparency with which the psychiatrist expressed their alternative position and viewpoint. Communication skills literature has also highlighted that a failure to fully establish the patient's understanding as well as a failure to express and demonstrate one's own position

when making decisions about treatment are likely to result in disagreement and resistance. In these cases empathic objectivity is recommended rather than implied scepticism or rejecting the patient's opinion out of hand (Platt & Gordon, 2004). Therefore, as demonstrated in the current study, and recommended in communication skills literature more widely, opposing views and disagreement in consultation are not necessarily indicative of a bad therapeutic relationship or poor outcomes and should not be avoided or only implicitly stated on this basis. Rather, open exploration of alternative views and transparency of one's own position when there is opposition are likely to result in a better outcome.

Fear of disagreement with patients about psychotic symptoms and the impact of this on the therapeutic relationship may be one reason that psychiatrists are reluctant to talk with patients on this topic (McCabe et al., 2002); however, in the current study there was no difference in patient or psychiatrist ratings of the therapeutic relationship given after the consultation regardless of whether or not the consultation had included discussion of psychotic symptoms. This was the case in spite of evidence of opposition and disagreement in some discussions. Therefore, this finding suggests that talking about psychotic symptoms, even when this results in disagreement, does not negatively impact the therapeutic relationship. Furthermore, patients appeared to respond particularly positively in instances where psychiatrists were transparent in their own views, and sensitive to those of the patient, a finding inline with communication skills literature, pointing to certain ways that resistance and disagreement can be successfully negotiated during consultations.

*Positive talk*

Although 40% of the extracts included statements of empathy, positive talk or reassurance, these statements often occurred in isolation in any given extract, in contrast with other processes such as information gathering questions. This was a surprising feature of the data given the personal and emotional nature of the accounts that patients often gave of their psychotic symptoms. Where positive talk did occur it was favourably received; however it was often more noticeable by its absence than by its presence. Communication skills training programmes are now widely recommended for clinicians working in healthcare, particularly in certain areas such as oncology and palliative care. They are an increasingly prominent

component of undergraduate medicine training courses, although few have been developed specifically for communication skills in psychiatry. One feature shared by all communication skills programmes is the emphasis on building a therapeutic relationship with patients. Expressing empathy, giving appropriate reassurance, and giving positive feedback and encouragement, are all widely recommended practices that help in achieving this goal (e.g. Silverman, Kurtz & Draper, 1998). In the context of patients with psychosis, a clinical group renowned as 'difficult' in terms of engagement and establishing a therapeutic relationship (e.g. Hinshelwood, 1999), it is surprising that psychiatrists are not utilising these communicative practices more frequently, particularly in response to emotionally salient topics of discussion. Seale and colleagues (2007) reported a similarly low rate of engagement with patients' concerns describing only three examples from extracts from 92 psychiatric consultations that included supportive listening and empathetic and reassuring responses. The researchers highlight the point that it is not always necessary to be able to solve a patient's problems in order to attend to their concerns giving an example of how sympathetic listening and seeking to understand the patient's experience and perspective resulted in the patient feeling satisfied that their concerns had been heard, even when the 'solution' offered by the doctor was not accepted. 'Normalising' the psychotic experience is also a key process of engagement and treatment recommended in CBT for psychosis (Kingdon & Turkington, 1991) as a way to reduce the patient's sense of being different or abnormal and to reduce distress associated with these concerns. Positive talk such as expressions of empathy, and giving reassurance or normalising are recommended practice when working with all clinical groups, and yet there is even greater rationale for utilising these practices in working with patients with psychosis. Communication between psychiatrists and patients with psychosis is likely to be enhanced by greater use of these practices.

*Treatment options*

Where psychiatrists mentioned a treatment option to patients during discussion of psychotic symptoms this was predominantly medication with occasional reference to daytime activities. Given the orientation of psychiatry and the presiding model of psychosis being medical it is not surprising that medication was most frequently referred to by psychiatrists. However, the contrast to patients, who referred more frequently to daytime activities as a way of coping with psychotic symptoms whilst

rarely mentioning medication, highlights the possibility that patients and psychiatrists views differ with respect to the usefulness of medication. If a psychiatrist were to follow the principles of SDM, issues such as this would be openly discussed in consultation with all possible treatment options addressed and understanding of these reached before jointly deciding on a course of action. The possibility that psychiatrists and patients discussed treatment options more broadly in other parts of the consultation cannot be ruled out, as well as consideration given to the fact that these consultations were routine and would not necessarily require the establishment of treatment preferences every time. However, even though psychiatrists often spoke with patients in a collaborative manner about the optimal dosage of medication and preferential patterns of adherence, these conversations usually made the explicit assumption that medication was the chosen treatment approach and did not explicitly question this. In spite of current recommendations for psychological therapy as a first line treatment for psychosis, psychological therapy was only mentioned during three discussions of psychotic symptoms. Reasons for this could vary from having discussed psychological therapy in the past, the patient already receiving psychological therapy, mention of it in another part of the consultation, or low resources for psychological therapy locally. However, Kingdon and Kirschen (2006) found that even when CBT was available psychiatrists chose not to refer 49% of patients with psychosis believing them to be unsuitable for the treatment due to perceived issues such as being unlikely to engage. Psychiatrists are the clinicians responsible for their patients' treatment and have a key role in alerting patients to all recommended forms of treatment and facilitating access to these where required. Psychological therapy is now recommended as a first-line treatment for psychosis (NICE, 2014) and where it is available it should be introduced, described, recommended and referred for. Further research exploring possible obstacles to referral to psychological therapy for psychosis is needed.

Overall, the results of the thematic analysis showed that psychiatrists often engaged with patients in discussing psychotic symptoms. There was a marked discrepancy at times in relation to what the patient chose to share when discussing their psychotic symptoms and what the psychiatrist wanted to know as demonstrated by the questions they asked. This incongruity is of interest when thinking about both the features of psychosis that are deemed salient to psychiatrists compared with those that are important to the patient, and the aims and objectives of psychiatric

consultations from the perspective of the psychiatrist and the patient. A number of opportunities for psychiatrists to build on their practice when talking about psychotic symptoms were identified inline with communication skills recommendations, psychological models of psychosis and the patient-centred care model. However, although areas for consideration and possible optimisation of psychiatric practice with regards to discussing psychotic symptoms have been identified, positive elements were also established. For example, despite possible fears by psychiatrists to the contrary, talking about psychotic symptoms during the consultation had no adverse effects on the therapeutic relationship from the perspective of the patient or the psychiatrist. Furthermore, these discussions did not take over the consultation and take up significant amounts of time. In fact there were no differences in length between consultations that included discussion of psychotic symptoms and those that did not, and psychotic symptoms when discussed only took up approximately 16% of the consultation.

### *4.4 Limitations and strengths of the study*

These findings should be considered within the context of the limitations and strengths of this study. The sample of psychiatrists and patients were to some degree self-selected insofar as they had to consent to participate, and it is possible that those psychiatrists and patients who declined to participate were different in some way from the sample included in the study. Moreover the potential participant pool included only those patients who attended their outpatient appointment and patients with organic brain disorder or substance misuse problems, as well as patients who did not speak fluent English, were excluded from the sample. These factors impact on the generalisability of the findings. Another limitation is that the study only reflects patient and psychiatrist interactions in routine outpatient settings; whereas psychiatrists work with patients with psychosis across a number of different settings in addition to routine outpatient clinics including inpatient wards and crisis and assertive outreach clinics. Furthermore, the data were collected in East London, and do not represent the diversity of patients and psychiatry services in different locations. In terms of the relationship between each patient and psychiatrist pair, the length of the relationship varied greatly with some pairs having worked together for many years, whereas other pairs were meeting for the first time. Although this variety could arguably be representative across a range of lengths of relationships, data on the length of the relationships were not available

and it was not possible therefore to explore this factor as a variable. Another possible limitation, as already mentioned previously in the discussion, was that the current data characterise only how patients describe psychotic symptoms in the context of the psychiatric consultation. Although this context is of interest and relevance to the aims of the current study, the findings are not necessarily generalisable to how patients might describe their psychotic symptoms in other contexts. A general limitation of qualitative research is that participants are aware of being observed. In this study participants were aware that the consultation was being filmed and this may have impacted on how they conducted themselves during the consultation. This point is particularly relevant in the case of the psychiatrists who might have moderated their behaviour and communication style on the basis that others might judge their performance. Although it is difficult to know whether this was the case, the recording equipment was very discrete, and anecdotally participants reported not being influenced by its presence.

At the level of analysis a number of limitations should be considered. Symptoms were not always easy to categorise with delusions often being coded under a number of different types, and hallucinations being difficult to define when a patient reported having a "feeling" about the presence of another being but without giving explicit details. This serves to highlight the variety of psychotic experiences that patients have, and the difficulty of categorising them using any sort of system. Although inter-rater reliability was presented on aspects of the data analysis such as the identification of extracts including discussion of psychotic symptoms and determining who initiated and ended discussions, a Kappa statistic was not reported. Furthermore, inter-rater reliability was not collected to support the application of codes in the data. This data would have further strengthened the validity and reliability of the analysis. The analysis included only the first instance of a discussion about each psychotic symptom and as such might have missed important aspects from later discussions, although there were not many instances when the discussion occurred more than once. No data were collected to distinguish instances where the topic of psychotic symptoms was raised in the consultation and their presence denied, from those where there was no mention of psychotic symptoms at all. This data would have provided useful information about the incidence of psychiatrists asking about psychotic symptoms during consultations. In addition, relational aspects or the interactions and levels of engagement were not

possible to study using thematic analysis. Future research could attempt to operationalise relational aspects and engagement during interactions and explore these factors (e.g. Federico et al., 2011).

The study also had a number of strengths including the large sample size for a naturalistic, observational study whereby 143 consultations were analysed. This large sample size enabled the combination of quantitative and qualitative analyses allowing for verification of aspects of the data such as the clinical levels of positive psychotic symptoms in relation to the disclosure of psychotic symptoms in the consultation, as well as the comparison of data on the therapeutic relationship between different groups. In addition there was variance in the patients' symptoms as well as their demographic characteristics adding to the generalisability of the study in these respects. A further strength of the study was that the descriptions that patients gave of their symptoms were free of the influence of predetermined research questions, and as such can be argued to be more valid on this basis. Although the context of the study, i.e. psychiatric consultations, likely impacted on how patients described their symptoms, this is seen as a strength of the current study, as rather than purely exploring the phenomenological experiences of patients with psychosis (the description of which would always be somewhat context dependent) the aims were also to explore what aspects of their experience patients would choose to share with the psychiatrist as well as considering the response of psychiatrists to these disclosures. The benefit of an observational, qualitative study of this nature is the ecological validity of the data. Collecting naturalistic data in a healthcare setting has great value for assessing and developing clinical practice. For example, psychiatrists have to manage the time pressures and other responsibilities of their work, and rarely have the opportunity to observe the practice of others (Seale et al., 2005). Therefore, this study offers the opportunity for psychiatrists to learn more about this topic whilst being exposed to other examples of clinical practice.

### *4.5 Clinical implications and areas for future research*

Although there is a need to be cautious in making recommendations on the basis of a one-off study of this nature, a number of clinical implications can be tentatively drawn from the findings. Firstly, psychological models of psychosis are further validated by the finding that the same aspects of positive psychotic symptoms as

those emphasised by these models were salient to patients, even in non-psychological contexts and at times when they were not being directly asked about these features of psychotic symptoms. The symptom characteristics identified as significant to patients were not reflected in the focus of psychiatrists' questioning, indicating a potential need for psychiatrists to incorporate issues important to patients into the psychiatric consultation inline with a patient-centred model of care. Clinically psychiatrists may have reservations about talking to patients about particular aspects of their psychotic symptoms; however, the findings of this study suggest that talking about psychotic symptoms did not have negative consequences insofar as it was not overly time-consuming, collusive with the patient, or damaging to the therapeutic relationship. Furthermore, disagreement about psychotic symptoms did not have negative consequences provided that the psychiatrist communicated their position in a transparent and sensitive manner. Previous research has suggested that avoidance by the psychiatrist of discussion of psychotic symptoms can result in disagreement and dissatisfaction on the part of the patient (McCabe et al., 2002). Moreover, the current study indicates that discussing psychotic symptoms does not have a negative impact on outcomes. Therefore, talking about psychotic symptoms in psychiatric consultations should at the least not be avoided, and should be encouraged where it is in accordance with the priorities of the patient.

The current study was not able to operationalise different 'levels' of discussion about psychotic symptoms from the perspective of the patient or the psychiatrist, for example the level of engagement in the discussion. In addition, it was not possible to compare outcomes on the basis of factors such as level of engagement or discussion of different features of psychotic symptoms (e.g. did discussion about the frequency of a psychotic symptom have a differential impact to discussion of the personal meaning?). It is possible that the inclusion of discussion around positive psychotic symptoms has a beneficial effect on psychiatric outcomes. The level of engagement by both parties in the discussion, or the particular features of the psychotic symptoms discussed, may further enhance this positive effect. Future research could aim to explore these questions.

### *4.6 Conclusions*

There is growing evidence to suggest that patients wish to talk about their psychotic

experiences, and that it is beneficial in the context of psychotherapy. The current study is the largest of it's kind using qualitative methods to explore discussion of psychotic symptoms in psychiatric consultations. The findings are novel in showing that patients wished to talk about their positive psychotic symptoms in psychiatric consultations, and those features that were most salient to them did not correspond with the typical focus of psychiatrists, but more closely resembled those highlighted by psychological models of psychosis and were raised unprompted. Concerns that psychiatrists may have about talking about psychotic symptoms are likely unfounded as when discussion of psychotic symptoms occurred it was not time consuming, colluding, or damaging to the therapeutic relationship. Even when disagreement occurred about the basis for the symptoms, when psychiatrists were transparent and sensitive in describing their own stance no difficulty arose. In order for psychiatry to become more inline with patient-centred models of care, psychiatrists should be further acknowledging the concerns and agenda of patients in the psychiatric consultation.

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**APPENDICES**

**Appendix A:** Scale To Assess Therapeutic Relationships in Community Mental Health Care (STAR), clinician and patient versions.

**STAR**
**Scale To Assess Therapeutic Relationships in Community Mental Health Care**
**Clinician Version**

| | **Never** | **Rarely** | **Sometimes** | **Often** | **Always** |
|---|---|---|---|---|---|
| | 0 | 1 | 2 | 3 | 4 |
| 1. I get along well with my patient. | | | | | |
| 2. My patient and I share a good rapport. | | | | | |
| 3. I listen to my patient. | | | | | |
| 4. I feel that my patient rejects me as a clinician. | | | | | |
| 5. I believe my patient and I share a good relationship. | | | | | |
| 6. I feel inferior to my patient. | | | | | |
| 7. My patient and I share similar expectations regarding his / her progress in treatment. | | | | | |
| 8. I feel that I am supportive of my patient. | | | | | |
| 9. It is difficult for me to empathise with or relate to my patient's problems. | | | | | |
| 10. My patient and I are open with one another. | | | | | |
| 11. I am able to take my patient's perspective when working with him / her. | | | | | |
| 12. My patient and I share a trusting relationship. | | | | | |

**STAR**
**Scale To Assess Therapeutic Relationships in Community Mental Health Care**
**Patient Version**

| | **Never** 0 | **Rarely** 1 | **Sometimes** 2 | **Often** 3 | ***Always*** 4 |
|---|---|---|---|---|---|
| 1. My clinician speaks with me about my personal goals and thoughts about treatment. | | | | | |
| 2. My clinician and I are open with one another. | | | | | |
| 3. My clinician and I share a trusting relationship. | | | | | |
| 4. I believe my clinician withholds the truth from me. | | | | | |
| 5. My clinician and I share an honest relationship. | | | | | |
| 6. My clinician and I work towards mutually agreed upon goals. | | | | | |
| 7. My clinician is stern with me when I speak about things that are important to me and my situation. | | | | | |
| 8. My clinician and I have established an understanding of the kind of changes that would be good for me. | | | | | |
| 9. My clinician is impatient with me. | | | | | |
| 10. My clinician seems to like me regardless of what I do or say. | | | | | |
| 11. We agree on what is important for me to work on. | | | | | |
| 12. I believe my clinician has an understanding of what my experiences have meant to me. | | | | | |

**Appendix B:** Coded extract example.

**Patient 606, 00:10:50**

DISCUSSION INITIATED BY PATIENT

**Patient** Yeah, more in the past, but it's like when I wake up someone's took control of me. I just can't control the environment kind of thing. I can't control my action or anything...

**Doctor** When you say someone's taken control you could I just ask you what do you mean by that?

**Patient** Well, it feels like there's a presence around like they don't want me to sleep.

**Doctor** Who doesn't want you to sleep?

**Patient** I don't know.

**Doctor** But there's someone out there?

**Patient** Yeah, yeah...

**Doctor** And can it control you in any other way, apart from not...

**Patient** No, it's just...

**Doctor** Stopping you sleep?

**Patient** ...just in my day to day dealings, you know, I lose like my lack of concentration and everything. Irritability, you know, I get a little bit irritable and restless, and just can't sleep, you know?

**Doctor** But you don't feel they can control you in any other way like your thoughts or your emotions in any way? Can they make you feel sad or depressed?

**Patient** They can do, yeah, I mean it depends on these are talking to. It all depends who I'm with, you know what I mean? Yeah, it just feels like there's a visible force and I've got no control over it, and I just have to go along with it.

**Doctor** How do you sort of know there's a force, just so I can answer?

**Patient** Well, it's just a feeling, that there's something not right, you know?

**Doctor** Do you really believe that there is a force that's kind of doing these things?

**Patient** Yeah.

**Doctor** How strongly do you believe it?

**Patient** Quite strongly. It feels so strong anyway. You know, for me to wake up and...

**Doctor** Do you care to rate how strongly you believe it? Say from zero to 100%? How strong would say you really believe that there's a force out there?

Control

Identity

Intention

Examples of information gathering questions

Emotional response

Exploring patient's meaning

Delusional explanation

**Patient** Oh, easy, easy 80%.

**Doctor** But not 100%?

**Patient** Err, well, yeah, 100%, but...

**Doctor** Which one is it, is it 80% or a 100%?

**Patient** I was in between...

**Doctor** In between, yeah, so it's not quite 100, but close to 90%.

**Patient** Yeah, okay.

**Doctor** Do you think there's a possibility that this could be in your mind?

**Patient** Well, it's definitely in my mind; it's definitely a thought in my mind.

**Doctor** What I mean is, is it possible that you could be wrong about this, that there is no force out there. That this is just something in your mind possibly? That you've been mistaken.

**Patient** Yeah, yeah.

**Doctor** Could have been part of a mental [PHONE RINGING] illness such as schizophrenia? Possibly? Excuse me for a second. Hello. Yes. Thank you bye. I apologise for that.

**Patient** Okay. No, it just sometimes gets difficult, you know, you sit there and your minds everywhere other than where it should be, do you know what I mean?

**Doctor** Difficulty concentrating.

**Patient** Yeah, sure. I mean I know people want me to go back to work and sometimes I feel like I wanna go back to work. Apparently I have to work now until I'm in my seventies or something. The retirement is going up.

DISCUSSION ENDED BY PATIENT VIA A CHANGE IN TOPIC.

Exploring patient's meaning/ implicit explanation giving

Disagreement

**Appendix C:** Additional extracts to evidence themes.

**PATIENT DISCLOSURE**

***Hallucinations***

Identity

*Doctor And then you have given these voices names?*
*Patient Yeah.*
*Doctor You have these voices names or did they give these voices*
*Patient Well Don give me his name*
*Doctor Yeah.*
*Patient And and I don't know I cant remember how I got the other ones. [Patient 1202, 00:04:02]*

Relationship

*Patient And I watch tele by myself when school come then then I watch the TV. I watch TV with them.*
*Doctor You watch TV with them?*
*Patient With them sometimes. [Patient 107, 00:04:04]*

*Patient Yah what it is well some of them owe me money and things like that.*
*Doctor The voices owe you money?*
*Patient They owe me money and this is this is that is what they say.*
*Doctor OK*
*Patient I don't know what to do, I want to get my money back I dunno.*
*Doctor How much do they owe you?*
*Patient He owes me a lot of money.*
*Doctor OK. [Patient 107, 00:06:35]*

Intention

*Doctor What do they say?*
*Patient Well "things are gonna get better for me". "Things'll get better". "I'm on the mend", "I'm on the mend", they told me "I'm on the mend".*
*Doctor What do you mean?*
*Patient On the mend of getting better.*
*Doctor Ah ok. Things um, so basically they say encouraging things to you?*
*Patient Nice, lovely yes "get well" yeah. They're proud of me. [Patient 301, 00:04:50]*

*Doctor Now I know they tell you to do odd things like crawling on the floor, or hop, is that right? So have you been doing it or you have you been able to resist and not doing it?*
*Patient I have been able to resist and not…*
*Doctor Able to resist not doing it ok that's a good thing*
*Patient Yes [Patient 302, 00:02:52]*

*Doctor What kind of things does the voice say?*

*Patient "Try and do better for yourself." "Try and keep yourself clean and tidy." It's positive things sometimes and then sometimes it's negative. I don't know.*
*Doctor What kind of things do they say when it's negative? I know it's quite difficult to talk about but can you remember the last time it said something negative to you?*
*Patient "Carry a knife" and all that. "Carry a knife". [Patient 2601, 00:01:30]*

Commands, power and control

*Doctor Do they give you instructions about what to do and what not to do?*
*Patient Yeah sometimes. No they make me, just nasty things.*
*Doctor Ok. Do you feel compelled to follow these instructions?*
*Patient Sometimes.*
*Doctor What would happen if you don't follow their instructions?*
*Patient I don't know.*
*Doctor Do you think something bad will happen?*
*Patient Probably.*
*Doctor But you have never tried it? [Patient 1202, 00:05:49]*

*Doctor And do they, can they take control over you, over you by any chance?*
*Patient Um, it's a rarity but they have.*
*Doctor In what sense?*
*Patient My movement and stuff like that. Uh, even, even, I mean going years back, um, I lost, I used to, I'm right handed, I'm a right-handed person.*
*Doctor Right.*
*Patient And I brush my teeth with my right but I lost the ability to brush my teeth with my right hand so I had to start brushing my teeth with my left hand.*
*Doctor Why is that?*
*Patient I don't know just went…*
*Doctor Is that because of the voice command?*
*Patient I think so, yes. [Patient 1102, 00:13:21]*

***Delusions***

*Doctor And how would they know they are what you are thinking?*
*Patient Because they're probably a higher intelligence than us. We don't know the difference. They probably look the same as us but they're different. They might have been here before us. But they're not human, they're just not human.*
*Doctor Okay.*
*Patient And they're called the (###) species but half of them they know everything. [Patient 1006, 00:10:54]*

*Patient So I do believe that there is some kind of reading minds out there but I don't know exactly to the extent of how far it goes, you know.*
*Doctor Okay, okay.*
*Patient I wouldn't say everyone and I wouldn't say no-one; I would say there's some kind -*

*Doctor There's something going on.*
*Patient Oh there's something going on, yeah. I don't know what or how or when but something is going on in my opinion. [Patient 601, 00:26:36]*

*Patient I feel like, like I'm being used in a kind of avatar way, anyway. So it's a constant struggle to deal with people that I consider to be different entities.*
*Doctor Okay. So where are these people from? These people who have…*
*Patient I just, I refer to them as a kind of golden circle.*
*Doctor A golden circle?*
*Patient A circle of people who are capable of communicating in the same way that I am and have…*
*Doctor Are aware as you are.*
*Patient Yeah, and are capable of projecting reality in the same way, because that's basically what I'm claiming that I do, that I project reality. [Patient 903, 00.09.30]*

*Patient Sometimes you're wary; you might walk into trouble what you want to avoid. You might get somebody that's come out and dislikes you; gives you bad looks. [Patient 601, 00:22:24]*

***Explanatory Model***

Medical

*Patient Well, quite honestly, when you're behaving irrationally you're not always positive what you're saying, and I do get very forgetful. Since I've had all these problems I can't always remember what I say and what I do.*
*Doctor Right, so from the look of things, looking back now do you understand that…?*
*Patient I realise what I've probably been doing, but at the time when you get paranoid you don't always realise what's happening to you.*
*Doctor Okay, so from the look of this you actually understand what's happened in the past?*
*Other Once we'd talked about it yes.*
*Doctor That it was just your mind playing…*
*Patient It's my mind playing tricks on me. [Patient 2501, 00:08:58]*

*Doctor By saying that you know that they're voices, what do you mean by that? It's a good thing that you said but…*
*Patient Well, I could hear my mother calling out my name. I know my mother's dead and I know she's not around but I hear her calling out my name in my head, you know what I mean, so I know they're voices.*
*Doctor Yeah. So they're things that are not real as such?*
*Patient No the things are not real.*
*Doctor Yeah. Did you always think that?*
*Patient No, I used to believe in the voices that I heard. I used to think people were communicating with me telepathically and I used to respond. [Patient 201, 00.03.45]*

*Patient But I should say that I am sane enough to realise that's what's going on.*
*Doctor Do you mean that the logos might not have anything to do with you, but you start that it might have something to do with you?*
*Patient Yes, but I always win the argument on the side of sanity and realise it's not. [Patient 204, 00:05:25]*

Spiritual

*Doctor Okay, so these voices that you have heard. Where does it come from?*
*Patient Sometimes it is very enlightening, like it could be a god or a nice spirit who is trying to guide me. [Patient 1204, 00:05:26]*

*Patient And I always pray I still have my faith in the Lord you know and I know like people might misunderstand you know that how could you listen to God you know if you sort of hear a full pattern but it is like a full pattern you know I one thing I always I pray.*
*Doctor And what are you listening to God or have you listened to God in the last lets say few weeks?*
*Patient Oh yeah I listen to God all the while you know? It's you know It's this thing that you know that the Christian has faith in and you know and erm–*
*Doctor But what you mean is that you hear the voice of God? Or are you talking symbolically metaphorically?*
*Patient Symbolically probably but you know sometimes I mean people will question this you know you do hear a voice you know from the Lord and you know you know and it's a constructive thing you know [Patient AP010, 00:02:30]*

Supernatural

*Doctor How strongly do you believe it?*
*Patient Quite strongly. It feels so strong anyway. You know, for me to wake up and...*
*Doctor Do you care to rate how strongly you believe it? Say from zero to 100%? How strong would say you really believe that there's a force out there?*
*Patient Oh, easy, easy 80%.*
*Doctor But not 100%?*
*Patient Err, well, yeah, 100% . [Patient 606, 00:12:46]*

*Doctor Do you get the feeling that sometimes you are not what you think you are?*
*Patient Yeah.*
*Doctor That you are a different person.*
*Patient Yes I do feel like that.*
*Doctor Ok.*
*Patient I don't think I'm from this planet. [Patient 1202, 00:09:24]*

Delusional

*Doctor What made you think though that you've you've committed any crimes?*
*Patient Well the tor- the torture that I'm getting. It makes me think that I'm fucking (###) or something. It made me think that I've gone*

*and raped some very little kids and I'm being tortured. And the hell, it's like someone's put me in (###)view. But I can't remember doing any of things so then it weren't me so I don't know. [Patient 1001, 00:05:41]*

***Emotional response***

Distress

*Patient Aggressive and worrying it was, yeah. I was upset, I don't know what I was doing, I was confused. I didn't know whether I was coming or going. I didn't know what was going on. [Patient 2601, 00:05:17]*

*Patient My thoughts are more upset than voices. My thoughts are terrible sometimes I sit there thinking all sorts of things. [Patient 606, 00:07:38]*

*Patient They drive me up the wall I mean*
*Doctor I mean can you cope with them?*
*Patient Well, er, it's not very nice being tormented all the time, is it? It's not nice at all, you know. They keep bothering me. [Patient AP051, 00:09:22]*

Fear

*Patient It depends on how my day's been. If my day's been, some days, some days, some days I come out the house and I don't want to come out the house. And I come out of the house and it's been a horrible experience. It's not bound to how I feel its other people are as well. Sometimes you're wary; you might walk into trouble what you want to avoid. You might get somebody that's come out and dislikes you; gives you bad looks. [Patient 601, 00:22:24].*

*Doctor What do you think is gonna happen if you leave the house?*
*Patient It's... I guess its fear of getting attacked, you know, every time I see like boys with hoods and that. I get scared, you know, and at the same time I'm scared of what I might do, you know? [Patient 607, 00:07:42]*

Confusion

*Patient Yeah, I know it's silly, but I've got this bug in my head. It's funny. I should just say that because also I wanted to talk to you. Sometimes when I'm asleep, you know like you go in and out of consciousness? Anyway, I'm asleep sometimes and in my mind's eye I keep seeing insects in my head. This is really hard to explain. I mean it's not scary and it's not debilitating. But as my eyes are shut and could focus sometimes with my eyes and I see insects go across my eyes. They're never the same insects they're always different. I'm thinking, you know, could my dreams be so vivid that I could see it all the time? [Patient 204, 00:14:25].*

*Patient I don't see it getting up and walking it's just like a hand moving sort of thing. I see that all the time. I look at it but it puzzles me.*
*Doctor It puzzles you*

*Patient A bit yeah. [Patient 101, 00:07:38]*

*Positive or neutral feelings*

*Doctor Does it distress you?*
*Patient No I don't care anymore [Patient 1006, 00:11:19]*

***Coping strategies***

Ignoring or resistance

*Doctor Cool and how would you cope with them when you do hear?*
*Patient I just sort of you know like if your at a party and your talking to someone and there's much more interesting conversation going on elsewhere…*
*Doctor Right.*
*Patient It's that strategy that you use to stick with whom you're talking to, to be polite basically so if I'm sort of- do you I'm kind of saying you know what, I don't know, can't really explain it better than that, yeah. [AP019, 00:02:05]*

*Patient At that time it did, yeah. But now I just ignore any voices that comes into my head. Like if it's God or not, you know, I mean I have my thoughts and although I know what's logical now, more so than what's emotional. [Patient 201, 00:05:53]*

Daily activities and hobbies

*Doctor So when you get stressed, how do you manage to cope with these voices or images?*
*Patient Person and things, smoke a roll up.*
*Doctor Cigarette you mean or drugs?*
*Patient No, cigarettes, yeah. [Patient 1104, 00:08:16]*

*Doctor Yes, yes. And how do you cope with these voices?*
*Patient Plenty of rest.*
*Doctor Right, okay.*
*Patient I get rest, I get fresh air.*
*Doctor Right, okay.*
*Patient I don't think that seems to be the answer though and I think maybe, maybe exercise. [Patient 1601, 00:03:32]*

**PSYCHIATRIST FOCUS**

***Positive talk***

*Doctor And I believe you get very distressed about this yes? Ok. [Patient 1202, 00:04:48]*

*Doctor Some people experience that where they're hearing their own thoughts, or their own actions. [Patient 201, 00:06:37]*

*Doctor You try, well that's good. [Patient 602, 00:05:34]*

***Exploring patients' meaning***

*Doctor Why do you think that was triggered? What do you think has brought it on? [Patient 1106, 00:06:51]*

*Doctor Okay. And with regards to these voices, cause you've had them for a long time, what, what do you think in terms of, where do you think they're coming from? [Patient 602, 00:06:36]*

*Doctor: Could they actually take ideas out of your head? [Patient 206, 00:07:19]*

*Doctor Do you think there's a possibility that this could be in your mind? [Patient 606, 00:13:28]*

***Disagreement***

*Patient That's not, this is- this is what I hear, you know?*
*Doctor You think that's what you hear?*
*Patient This is what I hear. Conjectures in public places, even at home. [Patient 1501, 00:06:03]*

*Doctor Could have been part of a mental [PHONE RINGING] illness such as schizophrenia? Possibly? Excuse me for a second. Hello. Yes. Thank you bye. I apologise for that.*
*Patient Okay. No. It just sometimes gets difficult, you know, you sit there and your minds everywhere other than where it should be, do you know what I mean? [Patient 606, 00:13:49]*

***Treatment options***

*Doctor (DRUG NAME) Yeah I think that's probably we'd agree that's likely to be the one that most helped. That's particularly good at dealing with things like hearing voices. [Patient 2103, 00:04:25]*

*Doctor: Another source of help, which is, thinking about, around employment, is that we've got the Re- a Rework Service. [Patient 206, 00:08:21]*

***Explanation giving***

*Doctor At the time that it might be for you, but obviously now you're sort of looking back at it and you're saying that you don't think it was actually for you. Well, those kinds of messages that come through television or internet, or Twitter or whatever it is. And I think just based on some of those symptoms that you've had I think that's what we're basing the diagnosis on. Although I appreciate that there is sort of a hindrance of reality to this and there are some bits that are not quite right. Okay so that's the sort ...those are positive symptoms that we talk about.*
*Patient So I'm definitely suffering with it then?*
*Doctor Well, I believe you are.*
*Patient Well, it answers a lot of my questions. [Patient 606, 00:06:28]*

**Appendix D:** Letter of ethical approval.

**East London REC 1**
Room 24, 2nd Floor
Burdett House
Mile End Hospital
Bancroft Road
London
E1 4DG

Telephone: 020 8223 8602

Dr Rose McCabe
Senior lecturer
Queen Mary University of London
Academic Unit
Newham Centre for Mental Health
Glen Road
London E13 8SP

29 April 2010

Dear Dr McCabe

| | |
|---|---|
| **Study Title:** | **Developing and piloting a new intervention to improve psychiatrist-patient communication about psychosis: an exploratory cluster-randomised controlled trial** |
| **REC reference number:** | **10/H0703/12** |
| **Protocol number:** | **1** |

Thank you for your letter of 04 March 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

*Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| REC application | | 06 January 2010 |
| Covering Letter | | 05 January 2010 |
| Protocol | 1 | 23 November 2009 |
| Investigator CV | | 08 December 2009 |
| Participant Consent Form | 1 | 27 November 2009 |
| GP/Consultant Information Sheets | 1 | 03 December 2009 |
| Referees or other scientific critique report | | |
| Email from Funder | | 22 April 2009 |
| Initial Letter from Funder | | 25 March 2009 |
| Response for Funder Peer Review | | 01 April 2009 |
| Letter from Sponsor | | 11 January 2010 |
| Response to Request for Further Information | | 04 March 2010 |
| Referees or other scientific critique report | | 09 December 2008 |
| Questionnaire: CQS | 1 | 04 March 2010 |
| Questionnaire: MPCC | 1 | 04 March 2010 |
| Questionnaire: Patient Experience | 1 | 04 March 2010 |
| Questionnaire: STAR-P | 1 | 04 March 2010 |
| Questionnaire: STAR-C | 1 | 04 March 2010 |
| Letter to Consultant | 1 | 04 March 2010 |
| Buchanan 1992 | 1 | 04 March 2010 |
| Nuechterlein et al 2006 | | |
| Repair Protocol 2005 | | |
| Letter from Trust | 1 | 09 September 2008 |
| Participant Information Sheet: Patient | 3 | 04 March 2010 |
| Participant Information Sheet: Psychiatrist | 3 | 04 March 2010 |
| Participant Consent Form: Patient | 2 | 04 March 2010 |

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Now that you have completed the application process please visit the National Research

Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

| **10/H0703/12** | **Please quote this number on all correspondence** |
|---|---|

Yours sincerely

P.P. Senior Research Ethics Administrator
**A. T. Tucker BSc(Hons) PhD SRCS**
Chairman
East London Research Ethics Committee 1
(Formerly known as East London and The City REC)

*Enclosures:* *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers"
*Copy to:* *Ms Karin Albani, East London and City Mental Health NHS Trust*

## East London REC 1

## Attendance at Sub-Committee of the REC meeting on 28 April 2010

### Committee Members:

| *Name* | *Profession* | *Present* | *Notes* |
|---|---|---|---|
| Dr Chandan Alam | Experimental Pathology | Yes | |
| Professor Atholl Johnston | Professor of Clinical Pharmacology | Yes | |

# SERVICE RELATED RESEARCH PROJECT

# Factors influencing the effectiveness of a one-day CBT for insomnia workshop.

Supervisor: Dr June Brown

Southwark Psychological Therapies Service (SPTS)

**CONTENTS**

**ABSTRACT**

**Background:** Insomnia is highly prevalent and has severe negative consequences. Cognitive behavioural therapy for insomnia (CBT-I) is an evidence-based treatment, which targets factors that perpetuate insomnia over time. Using a format developed by Brown and colleagues (2000), offering self-referral, psycho-educational workshops in the community, one-day CBT-I workshops are run on a routine basis by Southwark Psychological Therapies Service (SPTS) for the general public. These workshops have been shown to be effective in reducing levels of insomnia (Prytys et al., 2010; Swift et al., 2012). However, less is known about the impact of factors indicating greater complexity or need, such as co-morbid depression or anxiety or receipt of previous treatment, on the effectiveness of the CBT-I workshop. A better understanding of these factors could help in moving towards a 'stepped care' model of treatment for insomnia (Espie, 2009).

**Aims:** To evaluate the accessibility and clinical effectiveness of a series of nine one-day CBT-I workshops (n=120) and to explore the impact of factors including co-morbid depression or anxiety and receipt of previous treatment, on the effectiveness of the CBT-I workshops.

**Results:** The CBT-I workshop was effective at reducing insomnia at one-month follow-up and broadly accessible across a wide group of people in the community in terms of age, employment and ethnicity. Furthermore, significant reductions in depression and anxiety were found and the severity of depression or anxiety at baseline did not interfere with the effectiveness of the workshop further evidencing the broad application of this intervention. People with no previous experience of counselling or psychological therapy showed greater reduction of insomnia symptoms following the workshop compared with those with previous experience.

**Conclusions:** The CBT-I workshop is an accessible and effective treatment for insomnia across a range of clinical severity and complexity. Further benefits include reductions in both depression and anxiety.

## 1 INTRODUCTION

### *1.1 Insomnia*

Insomnia describes a condition that occurs when a person is not able to get to sleep, to remain asleep or to get sleep that is restorative enough. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; APA, 2000), in order to be diagnosed with primary insomnia, a person must experience the symptoms for at least a month, and the symptoms must cause them distress or reduce their ability to function successfully. The symptoms cannot be caused by a different sleep disorder, a medical condition, or be a side effect of medications or substance misuse. Consequences of insomnia can include fatigue, poor concentration and memory. Symptoms of insomnia are being reported at an increasing rate and are currently estimated to be present in 38.6% of the UK adult population, with a clinical diagnosis of insomnia being present in 5.8% (Morphy et al., 2007). Increased risk for insomnia is associated with lower educational attainment, unemployment, a widowed, divorced, or separated marital status, female gender, and increased age (Ohayon, 2002). Furthermore, insomnia is highly co-morbid with depression and anxiety and has been found to predict their relapse (Ohayon & Roth, 2003). The economic burden of insomnia is significant with 76% of the estimated cost being due to absence from work and reduced productivity in the workplace (Daley et al., 2009).

### *1.2 Treatment for insomnia*

Insomnia is most commonly treated with pharmacotherapy, evidence for which indicates short-term benefits; however, there is no evidence that the effect is lasting (Riemann & Perlis, 2009; Smith et al., 2002). A growing body of evidence indicates that cognitive behavioural therapy for insomnia (CBT-I) is an effective and lasting treatment with between 70-80% of treated individuals reporting significant symptom reduction (Morin et al., 1999; 2006a). CBT-I constitutes components including stimulus control, sleep hygiene, sleep restriction, relaxation training and cognitive therapy, which in combination aim to support the individual in learning about sleep and adapting their behaviours and dysfunctional beliefs and attitudes about sleep. CBT-I is superior to drug therapy in durability (Jacobs et al., 2004; Morin et al., 1999; Siversten et al., 2006) as well as having the added benefit of not having any physical side effects. Patients report a preference for CBT-I above

pharmacotherapy (Vincent & Lionberg, 2001). Although less evidence exists, group CBT-I has also demonstrated efficacy (Espie et al., 2007; Morin et al., 2006a).

In spite of the recognised efficacy of CBT-I and the general acknowledgement of its superiority over pharmacological interventions, both in terms of durability and preference by patients, the provision of CBT-I in the UK is still very low. According to the NHS website CBT-I is recommended above drug treatment, but is only provided in Oxford, Bristol and Scotland at present ("Insomnia - Treatment", 2014).

### *1.3 Access to treatment for insomnia*

Further to the lack of provision of CBT-I another potential barrier to treatment is that of access. Access to treatment for insomnia may be impacted by factors such as willingness to go to the GP, perhaps due to perceived stigma or shame associated with mental health difficulties. In a telephone survey of the general population conducted in Canada, Morin and colleagues (2006b) found that only 42.3% of those people with diagnosable insomnia had consulted their GP regarding their sleeping difficulties. Additional barriers to seeking help might include a tendency to minimise problems, and a lack of awareness of treatment options available (Brown et al., 2010; Stinson, Tang & Harvey, 2006).

In the case that individuals do seek help for their insomnia their access to treatment is likely to be further hampered by inadequate guidelines. For example, available clinical guidance in the UK recommends against using pharmacological intervention to treat chronic insomnia, instead recommending "due consideration to non-pharmacological measures". However, there is no further definition or information regarding what these measures might be (NICE, 2004). The combination of unclear guidance on treatment options, a lack of availability of CBT-I, and barriers to help-seeking at the individual level all serve to further hinder progress in treating insomnia in the general population.

One solution to the problems of low provision, poor access and unclear treatment guidelines is a group workshop offered in the community that accepts self-referrals as well as GP referrals. Brown, Cochrane and Hancox (2000) have developed a format offering self-referral psycho-educational workshops for the community. These one-day CBT workshops are run on a routine basis by Southwark Psychological Therapies Service (SPTS) for the general public and are advertised and held in non-

medical settings such as libraries and leisure centres in order to reduce possible stigma or intimidation associated with more medical contexts. Studies have shown that these one-day CBT group workshops have been effective in reducing depression and anxiety (Brown, Cochrane & Hancox, 2000; Brown et al., 2004; Horrell et al., 2013), with improvements being maintained two years later (Brown et al., 2008).

More recently this model has been applied, with success, to the treatment of insomnia (Archer et al., 2009; Prytys et al., 2010). Swift and colleagues (2012) report the results of a randomised controlled trial (RCT) showing significant reductions in clinical levels of insomnia in those who attended a CBT-I workshop compared with waitlist controls. In addition, the workshop was found to be broadly accessible across different age, employment and ethnic groups in the local population, and client rated satisfaction was very high indicating high acceptability of this type of intervention as rated by participants themselves.

***1.4 Predictors of effectiveness – a 'stepped care' approach***

CBT-I workshops are effective at the group level in reducing symptoms of insomnia, and are designed to combat some of the possible barriers to accessing care identified above; however, they may not be a suitable treatment for all individuals. Espie (2009) presents an argument for a 'stepped care' approach to the treatment of insomnia, whereby patients are assessed on the basis of their level of need and an appropriate treatment level is offered. Stepped care is often conceptualised as a pyramid with high patient volume managed at the bottom using low-intensity treatments such as computerised self-help programmes, and higher intensity treatments including group (large and small) and individual therapies offered in progressively smaller volumes inline with greater need or complexity. Patients can be assessed and entered into the stepped model according to their level of need, and can be 'stepped-up' in the case of non-response to a lower intensity treatment. According to this model of care group therapy represents a less intensive treatment than individual therapy and has the benefit of being more accessible to a wider group of people as well as being more time- and cost-effective. However, group therapy may not be as effective as individual therapy for some individuals with more severe or complex needs.

Inline with Espie's model, individual CBT-I, which represents a higher intensity treatment according to the stepped care model, has been demonstrated as effective

across different clinical groups including middle age and older-age adults (Irwin, Cole & Nicassio, 2006) and those with insomnia associated with cancer (Espie et al., 2008). Espie (2009) reported that across a range of clinical trials no consistent pattern of demographic or clinical predictors of poor response to individual CBT-I was found, showing instead that CBT-I has an approximate 70% response rate regardless of severity and chronicity of presenting characteristics. Although the broad applicability of individual CBT-I has been demonstrated, the generalisability of group CBT-I workshops across different clinical groups has not yet been formally assessed. According to the stepped care model, greater severity or complexity, such as comorbidity with depression or anxiety, may impact on the benefits gained from workshops and consequently may require a more intensive individual treatment. In the RCT conducted by Swift and colleagues (2012), higher depression scores at baseline were associated with less improvement in insomnia symptoms following the workshop providing support for the suggestion that individuals with insomnia complicated by greater severity and co-morbidity with depression might require a more intensive, higher level intervention.

In a related point the impact of the CBT-I workshop on co-morbid depression or anxiety is not yet evident. Swift and colleagues (2012) reported that despite improvements in insomnia no significant reduction in depression symptoms was found following the workshop. In contrast, Prytys and colleagues (2010) reported a reduction in symptoms of depression in individuals who attended a CBT-I workshop, as did Archer and colleagues (2009), although neither study reported whether or not there was an impact of severity of depression symptoms on insomnia outcome. None of the studies exploring the effectiveness of CBT-I workshops have reported on anxiety outcomes.

Individual CBT-I has been reported to reduce symptoms of anxiety (e.g. Backhaus et al., 2001; Espie et al., 2001) and depression (Backhaus et al., 2001; Manber et al., 2008; Taylor et al., 2007); however, few studies examining treatments for insomnia have measured clinical outcomes beyond insomnia symptoms making it difficult to draw conclusions about the possible effect of depression or anxiety comorbidity on insomnia outcomes following treatment, or conversely the impact of insomnia treatment on comorbid depression or anxiety (Morin et al., 2006a). It is therefore unclear at present whether increased complexity in insomnia presentation, such as

comorbid depression or anxiety, interferes with the benefits of a CBT-I workshop therefore requiring more intensive individual treatment as recommended by the stepped care model. In addition the indirect impact of the CBT-I workshop on co-morbid depression and anxiety is not yet evident.

Other factors could also indicate greater complexity and chronicity of insomnia such as non-response to prior psychological treatment or relapse following previous recovery. Examining the impact of factors such as comorbidities and receipt of previous treatment on the efficacy of group CBT-I workshops could contribute towards the identification of people who are more or less likely to benefit from one-day CBT-I workshops, thus moving towards a stepped care approach to the treatment of insomnia.

### *1.5 Aims and hypotheses*

The main aim of the current study was to evaluate the accessibility and clinical effectiveness of a series of large-scale one-day CBT-I workshops delivered in South London. A further aim was to explore the impact of factors indicating greater complexity or need, such as co-morbid depression or anxiety or receipt of previous treatment, on the effectiveness of the CBT-I workshops inline with a stepped care model of treatment for insomnia.

The main study hypothesis was that the CBT-I workshop would be accessible to a broad range of individuals in the community demonstrating clinical need and would be effective in reducing clinical symptoms of insomnia as rated using the Insomnia Severity Index (ISI) at one month follow-up. Given the inconsistencies of previous findings no specific hypotheses were made regarding the impact of the workshop on co-morbid depression or anxiety. Similarly no hypotheses were made regarding the impact of co-morbidity with depression or anxiety or receipt of previous treatment on the effectiveness of the CBT-I workshop in reducing insomnia.

## 2 METHODS

### *2.1 Design*

Between November 2008 and May 2011 nine 'How to Improve Sleep' workshops were run in a public library in Southwark, South East London as part of a series of four programmes. Other workshops in the series included 'Improving Self Confidence', 'Managing Anger', and 'Handling Stress'.

Publicity material was distributed to libraries, GP practices, counsellors, health centres, community mental health teams, and leisure centres. The publicity material used A5 flyers titled 'How to Improve Your Sleeping - One day workshops to help you handle your sleeping problems better'. Each flyer advertised upcoming workshops and invited people interested in attending to telephone or email for further information. Only adults currently living or working in the borough were eligible to attend the workshops. No other exclusion criterion was used.

Individuals who self-referred were invited to attend a one-hour introductory talk. During these talks, the format and content of the workshops were described, any questions arising were answered and baseline measures (to evaluate clinical progress over time) were completed.

### *2.2 Workshop programme*

The workshop programme was derived from Morin and Espie (2003) and adapted into a 1-day large-group format. Sessions were led by two clinical or counselling psychologists, with general expertise in CBT, and an assistant psychologist. The 7 workshop sessions are shown in Table 1.

**Table 1.** Workshop sessions

| Session No. | Session Title | Contents |
|---|---|---|
| 1 | Sleep Basics | Information about sleep and the potential effects of inadequate sleep. |
| 2 | Model of Sleep Quality | Introduction to a CBT model of sleep quality- highlighting links between thoughts, feelings and behaviours. |
| 3 | Sleep Hygiene | Lifestyle factors and habits and how these can affect sleep. |
| 4 | Sleep Scheduling | Explanation of sleep restriction – a method of improving sleep efficiency.<br><br>Explanation of stimulus control. |
| 5 | Sleep thoughts | Cognitive techniques for managing thoughts related to sleep.<br><br>Explanation of attitudes and beliefs about sleep and their impact. |
| 6 | Sleep feelings (including pre-bedtime wind-down) | Scheduling a pre-bedtime wind down.<br><br>Relaxation. |
| 7 | Overview | Summary of the sessions. |

Participants were expected to attend the whole workshop. On average, approximately 30 minutes was spent explaining and discussing each method (e.g. sleep scheduling) with participants. The programme content and teaching format (small and large group exercises) was varied throughout to maintain the interest and engagement of the group. Information was simultaneously presented on colourful slides (including cartoons and diagrams) corresponding to manuals given to participants. The programme started at 9:30am and finished at 4:30pm, with three refreshment breaks during the day.

### *2.3 Measures*

Data were collected from participants at two time-points; at the introductory talk ('baseline'), and at a follow-up meeting four weeks after the workshop ('follow-up').

*Demographics and treatment-seeking questionnaire:* Socio-demographic data (gender, age, employment status and ethnicity) and information about previous help-seeking were gathered at baseline using a custom designed questionnaire. Questions relating to previous help-seeking included "Have you ever tried counselling or psychological help before? Yes/ No".

*The Insomnia Severity Index* (ISI; Bastien, Vallieres & Morin, 2001) is a 7-item self-report measure of impaired sleep found to have robust psychometric properties. Each item uses a custom 5-point Likert-scale (0-4) to obtain a rating of factors including severity of insomnia problem, dissatisfaction with sleep pattern, perceived noticeability of problem to others, distress associated with sleep problem, and interference of sleep problem with daily functioning. Scores are categorised into 'not clinically significant insomnia' (0-7), 'sub-threshold insomnia' (8-14), 'clinical insomnia (moderate severity)' (15-21) and 'clinical insomnia (severe)' (22-28).

*The 9-item Patient Health Questionnaire* (PHQ-9; Kroenke, Spitzer & Williams, 2001) is a self-report questionnaire measuring each of the 9 DSM-IV criteria of depression on a Likert-scale of frequency from 0 ("not at all") to 3 ("nearly every day"). The total score ranges from 0 to 27 and can be categorised into none (0-4), mild (5-9), moderate (10-14), moderately severe (15-19) and severe (20-27) depression. The PHQ-9 is a reliable and valid brief assessment tool for assessing severity of depression symptoms.

*The 7-item Generalised Anxiety Disorder scale* (GAD-7; Spitzer et al., 2006) is a screening and severity measure for symptoms of generalised anxiety disorder. Each item is scored from 0 ("not at all") to 3 ("nearly every day") with a total score ranging from 0 to 21. Scores of 0-4 indicate no generalised anxiety, 5-10 mild, 11-15 moderate, and 15-21 severe anxiety. The GAD-7 is a reliable and valid measure of severity of generalised anxiety symptoms.

## 3 RESULTS

### *3.1 Workshop attendance*

Between November 2008 and May 2011 nine CBT-I workshops were run. 120 people expressed an interest in the CBT-I workshop by attending the introductory talk or completing the baseline assessment. Of these, 95 people (79%) attended the workshops. Follow-up data was collected from 64 of the 95 people (66%).

### *3.2 Participant demographics and baseline clinical characteristics*

A summary of the socio-demographic details of participants is given in Table 2. Independent t-tests and chi-square tests for independence were conducted to compare demographic details and clinical characteristics of those who provided follow-up data with those who did not in order to discount the possibility of fundamental differences between these two groups. The only difference found was in age whereby the participants who provided follow-up were older on average (mean age 45 years) than those who did not (mean age 40 years; $t(84) = 2.12$, $p = 0.04$).

All subsequent analyses are completed with only those participants for whom follow-up data were collected.

Approximately two thirds of the group were female, with a wide age range from 25 to 77 years. The majority of people were between ages 35 – 64 years. In terms of ethnicity, 70% of the participants reported their ethnicity as White with the next largest group being Black or Black British participants (approximately 16%). A small number of people were Asian or Asian British or Mixed, and approximately 10% of the group reported their ethnicity as 'Other' or chose not to disclose their ethnicity. The proportion of participants who were employed, whether full-time or part-time, was 67.2%.

Of those participants who attended the workshop, nearly two-thirds scored within the moderate to severe clinical insomnia range on the ISI at baseline. Over two-thirds reported clinical symptoms of depression (PHQ-9 over 4) and over half reported clinical symptoms of anxiety (GAD-7 over 4), (see Table 3.).

**Table 2.** Socio-demographic details of participants

| | | n | % |
|---|---|---|---|
| **Gender** | *Male* | 21 | *32.8* |
| | *Female* | 43 | *67.2* |
| **Age** | *25-34* | 9 | *14.1* |
| | *35-44* | 20 | *31.3* |
| | *45-54* | 16 | *25.0* |
| | *55-64* | 10 | *15.6* |
| | *65-74* | 2 | *3.1* |
| | *75-84* | 1 | *1.6* |
| | *Missing* | 6 | *9.4* |
| **Ethnicity** | *White* | 45 | *70.3* |
| | *Mixed* | 1 | *1.6* |
| | *Asian or Asian British* | 2 | *3.1* |
| | *Black or Black British* | 10 | *15.6* |
| | *Other* | 1 | *1.6* |
| | *Missing* | 5 | *7.8* |
| **Employment status** | *Employed full time* | 27 | *42.2* |
| | *Employed part time* | 16 | *25.0* |
| | *Unemployed* | 10 | *15.6* |
| | *Full-time student* | 2 | *3.1* |
| | *Retired* | 6 | *9.4* |
| | *Full-time home maker or carer* | 1 | *1.6* |
| | *Missing* | 2 | *3.1* |

### *3.3 Clinical effectiveness*

Change in insomnia, depression and anxiety following the CBT-I workshop were examined using paired-samples t-tests. Table 3 provides details of baseline and follow-up scores, statistical tests and effect sizes.

**Table 3.** Baseline and follow-up scores, statistical tests and effect sizes.

| | **N** | **Baseline M (SD)** | **Follow-up M (SD)** | ***t*** | **Effect Size (Cohen's *d*)** |
|---|---|---|---|---|---|
| *Insomnia (ISI)* | 47 | 17.49 (5.81) | 12.17 (5.74) | 6.84** | 0.92 |
| *Depression (PHQ-9)* | 61 | 9.39 (6.07) | 7.22 (5.14) | 3.60** | 0.39 |
| *Anxiety (GAD-7)* | 61 | 8.59 (6.47) | 6.16 (5.29) | 3.75** | 0.41 |

**$p$<.01

A significant reduction in insomnia, as measured by the ISI, was found following the workshop with the mean score reducing from the moderate insomnia range to the sub-clinical level of insomnia range. The effect size was large ($d$ = 0.92) (Cohen, 1988, p.22). Both depression and anxiety significantly reduced following the workshop with effect sizes in the small ($d$ = 0.39) to medium ($d$ = 0.41) range respectively.

### *3.4 Predictors of clinical effectiveness*

*Co-morbid depression or anxiety*

Change in insomnia score (ISI change) was calculated by subtracting the follow-up ISI score from the baseline ISI score. A larger positive change score indicates greater reduction in insomnia symptoms. ISI change was positively correlated with ISI at baseline (r=.47, p=.001), indicating greater insomnia reduction in those with more severe insomnia at baseline. As a result baseline ISI was controlled for in the following analyses.

**Table 4.** Partial correlations between depression, anxiety and change in insomnia symptoms.

| | **ISI change** |
|---|---|
| | ***r*** |
| *Baseline PHQ-9* | -.17 |
| *Baseline GAD-7* | .04 |

Partial correlations were conducted to examine the relationship between baseline depression and anxiety and change in insomnia independent of the severity of the insomnia at baseline. No relationships were found between baseline depression or anxiety and change in insomnia symptoms indicating that the severity of depression and anxiety did not impact on the effectiveness of the CBT-I workshop in reducing insomnia symptoms (see Table 4.).

*Previous counselling or psychological therapy*

T-tests were conducted to explore between-group differences between those who had accessed counselling or psychological help before and those who had not. There was a greater change in ISI score in those people who had not accessed this type of help previously (mean change = 7.47, n = 15) than in those who had (mean change = 4.31, n = 32), ($t(45) = -1.95$, $p = .05$) suggesting that the workshop was more beneficial in reducing insomnia for those people without previous experiences of counselling or psychological therapy.

## 4 DISCUSSION

### *4.1 Summary of results*

The main aim of this study was to evaluate the accessibility and clinical effectiveness of a series of large-scale one-day CBT-I workshops delivered in South London. The workshops proved to be accessible attracting people from a broad age range, employment status and ethnicity and who were demonstrating clinical levels of insomnia, depression or anxiety. The workshop was effective in reducing insomnia, with analyses indicating a large effect size, and was also effective at moderately reducing both depression and anxiety. A further aim was to explore the impact of factors indicating greater complexity or need, such as co-morbid depression or anxiety or receipt of previous treatment, on the effectiveness of the CBT-I workshops inline with a stepped care model of treatment of insomnia. There was no significant impact of severity of baseline depression or anxiety on reduction in insomnia symptoms following the workshop. However, people with no prior experience of counselling or psychological therapy benefited more from the workshop, as indicated by greater reduction in insomnia symptoms, than those with prior experience.

### *4.2 Accessibility*

Access to the workshop was good with 120 people expressing interest and a high proportion of these going on to attend the workshop. More women than men accessed the workshop, which may indicate the higher proportion of women affected by insomnia (Ohayon, 2002) or the higher number of women likely to seek help (Morlock, Tan & Mitchell, 2006). The age range of people attending the workshop was broad spanning from 25 to 77 years old, with the majority of people falling between ages 35 and 65 years. The ethnicity of participants attending the workshop was mixed inline with the local population. In terms of employment status the workshop attracted predominantly people who were employed either full- or part-time. This finding is very encouraging as data suggests that services attract a lower proportion of people in employment (Bebbington et al., 2000), perhaps due to the inflexibility of services to see people outside of working hours. Likely factors contributing to the accessibility of the workshop include the provision of the workshop on a weekend day, as well as reducing the potential stigma attached to accessing psychological services via the diagnosis-free labelling and marketing of the

workshop, the neutral venues and access via self-referral. In spite of the broad accessibility of the workshop, which had no exclusion criteria, the people who accessed the workshop demonstrated a clear clinical need. Over two thirds reported clinical insomnia in the moderate to severe range at baseline, and a similar number reported clinical levels of depression. In addition, over half of the sample reported clinical levels of generalised anxiety. This finding goes against the suggestion that self-referral formats might attract people without a clinical need, or the "worried well" and further supports similar findings by Brown and colleagues (2005). The combination of accessibility of the workshop with evidence that participants had a genuine clinical need provides a good treatment model for future services aiming to promote access to psychological services by a wide variety of people who demonstrate a real clinical need.

### *4.3 Clinical effectiveness*

Further support for the effectiveness of one-day CBT-I community workshops in reducing clinical levels of insomnia are provided by this study. As hypothesised, on average insomnia reduced from the moderate insomnia range to sub-clinical levels of insomnia at four week follow-up, and this reduction represented a large effect size. This finding offers further supporting evidence for the effectiveness of CBT-I (Morin & Espie, 2003; Morin et al., 1999; 2006a), as well as its effective delivery in the format of a one-day group workshop (Archer et al., 2009; Prytys et al., 2010; Swift et al., 2012). Greater reduction of insomnia symptoms was seen in those with more severe levels of insomnia at baseline, supporting the use of this format even with those individuals with more severe insomnia.

In addition to having a large impact on reducing insomnia, significant reductions in both depression and generalised anxiety were found following the workshop. Evidence has been presented for the additional benefit of individual CBT-I in treating depression (Backhaus et al., 2001; Manber et al., 2008) and anxiety (Backhaus et al., 2001; Espie et al., 2001). However, the impact of CBT-I delivered in a group workshop format is less clear. Swift and colleagues (2012) did not find a significant reduction in depression symptoms following attendance of a CBT-I workshop, although they reported a trend in this direction compared with a control group. However, both Prytys and colleagues (2010) and Archer and colleagues (2009) reported a reduction in depression symptoms following attendance of a CBT-I

workshop. No previous studies of the CBT-I workshop have reported levels of anxiety; therefore the finding of a moderate reduction in generalised anxiety symptoms is novel. CBT is an effective treatment for both depression and anxiety (see Butler et al., 2006 for a review) and although the focus of the CBT-I workshop was on insomnia, the aim to identify and modify dysfunctional beliefs and attitudes and unhelpful behaviours is a universal principle of CBT and was possibly generalised by participants to their symptoms of depression and anxiety. Furthermore, insomnia, depression and anxiety are highly co-morbid (Ohayon & Roth, 2003) and a reduction in one is likely to have an impact on another if they are linked. It was not possible in the current study to establish whether insomnia was a primary problem, or whether it was secondary to depression or anxiety; however, the finding that symptoms of insomnia, depression and anxiety were all reduced is very positive and supports the benefit of this workshop in treatment of individuals with insomnia with comorbid depression or anxiety, and possibly those people for whom insomnia is secondary to depression or anxiety.

### *4.4 Predictors of effectiveness – a 'stepped care' approach*

One of the aims of the current study was to explore the impact of factors indicating greater complexity or need, such as co-morbid depression or anxiety or receipt of previous treatment, on the effectiveness of the CBT-I workshops inline with a stepped care model of treatment for insomnia (Espie, 2009). No relationship was found between severity of either depression or anxiety at baseline and reduction in insomnia at four-week follow-up after the workshop. This finding suggests that having depression or anxiety did not interfere with the benefits of the workshop in reducing insomnia.

Although insomnia is a common and disabling condition (Morphy et al., 2007), and a strong evidence base now supports the effectiveness of CBT-I in the treatment of insomnia (Morin et al., 1999; 2006a), there is currently little provision of CBT-I in the UK. In response to the need for greater provision and access to treatment for insomnia Espie (2009) presented a stepped care model with a hierarchy of need (measured by severity and complexity) being matched to a hierarchy of treatment increasing by intensity. Less intensive treatments are beneficial for treating greater volumes of people and are more time- and cost-effective. The finding that the CBT-I workshop is both accessible and effective at reducing the rate of insomnia even in

those individuals with more complex needs, such as greater severity of co-morbid depression and anxiety, is very positive. It implies that a relatively low intensity, and therefore more time- and cost-effective, treatment has broad-reaching benefits across a varied sample of the population in terms of age, gender, ethnic group and clinical severity and co-morbidity.

Another measure arguably representing greater complexity of need was previous experience of counselling or psychological therapy. In the current study it was found that individuals who had no prior experience of counselling or psychological therapy benefitted more from the CBT-I workshop, in terms of reduction of insomnia, than those with prior experience of counselling or psychological therapy. A number of reasons could account for this finding including the possibility that those people who had already had counselling or psychological therapy in the past may not have gauged additional benefit to that already gained previously. Alternatively, they may not have benefitted from previous treatment indicating a level of psychological treatment resistance. It might be hypothesised that those people who had had previous counselling or psychological therapy had more severe insomnia; however, the results showed that more severe insomnia indicated greater rather than smaller reduction of insomnia symptoms. Although previous experience of counselling or psychological therapy was assessed, the focus and timing of the therapy was not specified, and it is therefore difficult to generalise further about what factors might have caused the finding. Future research could explore factors such as the focus of prior psychological treatment or counselling, when it occurred, and whether it was beneficial in order to understand this finding better.

### *4.5 Limitations*

Some methodological weaknesses of the current study deserve consideration. There was no control group to compare findings against in order to establish whether the changes seen were due to attendance of the workshop or another factor. Whereas it is reasonable to assume that the finding of a reduction in insomnia was due to the effectiveness of the workshop based on previous findings comparing a treatment group with a control group (Swift et al., 2012), it would still be important to assess whether the novel findings reported in the current study such as the reduction of generalised anxiety are specific to people who have attended the workshop.

Follow-up was conducted one month following the workshop, and it would have been of interest to know whether the changes in insomnia, depression and anxiety were maintained longitudinally. Evidence for the maintenance of improvement at two-years follow-up following a similar CBT workshop for depression has been presented (Brown et al., 2008) suggesting that the effects of workshops of this nature are long-lasting.

The nature of the workshops themselves limited the degree to which rigorous controls could be placed on the sample in the current study. For example, due to the self-referral system and lack of exclusion criteria, the sample of individuals was self-selecting and heterogeneous. Full diagnostic interviewing was not possible or appropriate given the inclusive ethos of the workshop and as such it was necessary to rely on self-report questionnaire measures of symptoms. Without diagnostic interviewing it was not possible to determine whether insomnia was a primary disorder, or secondary to another disorder such as depression or anxiety; however, the fact that the workshop was effective at reducing insomnia, depression and anxiety irrespective of severity or primary diagnosis suggests that it is an effective treatment across a broad range of people and clinical need.

The CBT-I workshops took place in Southwark and were open only to Southwark residents and employees which limited the sample to that of a relatively deprived inner-city community. It is not possible to say therefore whether the findings of this study would be generalisable to other populations; however, the RCT conducted by Swift and colleagues (2012) found a significant reduction in insomnia following the CBT-I workshop across multiple sites suggesting the broader application of the workshop in different communities.

Finally at 34%, the attrition rate of the current study was somewhat higher than that reported in other studies exploring the efficacy of one-day workshops (e.g. Archer et al., 2009; Horrell et al., 2012; Swift et al., 2012). Collecting follow-up data depended largely on the efforts of researchers on the study in encouraging participants to attend a follow-up meeting or to complete a follow-up pack by postal return. There was no reason to think that participants did not want to provide follow-up data and the measures included were relatively brief; however, after attending the workshop for treatment it might have been the case that participants were not incentivised to

provide further information. A greater emphasis on the value of collecting follow-up data may have increased the rate obtained.

### *4.6 Clinical implications and future directions*

In spite of the methodological limitations described above, the current study has provided good evidence for the accessibility and application of one-day CBT-I workshops as an effective way to treat insomnia of varying severity as well as reducing co-morbid depression and anxiety across a broad range of people. This finding has broad implications for clinical practice given the current lack of availability of evidence-based psychological treatment of insomnia. CBT-I workshops are appropriate for up to 30 people at one time, and present a time- and cost-effective way to effectively treat insomnia across a large volume of people. Given the frequency of insomnia difficulties in the population (Morphy et al., 2007), and the cost of this in economic terms on society (Daley et al., 2009) this intervention represents an effective and timely option that could be considered for wider application across healthcare services inline with Espie's stepped care model of treatment of insomnia. There is some indication that some people, namely those who have received counselling or psychological therapy in the past, may benefit less from this intervention, and might require a more intensive form of treatment. This finding requires further exploration, but in the first instance could suggest screening individuals on this and other factors that indicate a need to 'step up' their care to a more intensive therapeutic intervention.

A broader clinical implication of the findings of the current study relates to the delivery of psychological therapy more generally. Access to psychological therapy is hampered by a number of issues ranging from individual factors, such as unwillingness to seek help due to stigma or lack of awareness of treatment, to service issues such as low referral rates due to poor guidelines or lack of provision within services. The CBT-I workshop evaluated in the current study represents a format that provides effective psychological therapy in the community in a way that is both cost-effective and accessible. Similar evidence has been reported in support of CBT workshops for depression (Horrell et al., 2013), indicating the potentially broad application of psychological therapy in this format. In recent years services have been moving towards greater access to psychological therapy, for example the Increasing Access to Psychological Therapies service (IAPT) which has adopted

features such as self-referral, which fits in with the one-day CBT workshops style of delivery.

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## **Appendix A.** Insomnia Severity Index

**Insomnia Severity Index**

The Insomnia Severity Index has seven questions. The seven answers are added up to get a total score. When you have your total score, look at the 'Guidelines for Scoring/Interpretation' below to see where your sleep difficulty fits.

For each question, please CIRCLE the number that best describes your answer.

*Please rate the CURRENT (i.e. LAST 2 WEEKS) SEVERITY of your insomnia problem(s).*

| Insomnia Problem | None | Mild | Moderate | Severe | Very Severe |
|---|---|---|---|---|---|
| 1. Difficulty falling asleep | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty staying asleep | 0 | 1 | 2 | 3 | 4 |
| 3. Problems waking up too early | 0 | 1 | 2 | 3 | 4 |

4. How SATISFIED/DISSATISFIED are you with your CURRENT sleep pattern?

| Very Satisfied | Satisfied | Moderately Satisfied | Dissatisfied | Very Dissatisfied |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

5. How NOTICEABLE to others do you think your sleep problem is in terms of impairing the quality of your life?

| Not at all Noticeable | A Little | Somewhat | Much | Very Much Noticeable |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

6. How WORRIED/DISTRESSED are you about your current sleep problem?

| Not at all Worried | A Little | Somewhat | Much | Very Much Worried |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

7. To what extent do you consider your sleep problem to INTERFERE with your daily functioning (e.g. daytime fatigue, mood, ability to function at work/daily chores, concentration, memory, mood, etc.) CURRENTLY?

| Not at all Interfering | A Little | Somewhat | Much | Very Much Interfering |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

**Guidelines for Scoring/Interpretation:**

Add the scores for all seven items (questions 1 + 2 + 3 + 4 + 5 +6 + 7) = _____ your total score

Total score categories:
0–7 = No clinically significant insomnia
8–14 = Subthreshold insomnia
15–21 = Clinical insomnia (moderate severity)
22–28 = Clinical insomnia (severe)

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